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ABSTRACT

Perceptions of 152 sets of parents of handicapped young children were investigated. Interviews were conducted focusing on five aspects: initial notification that they had a handicapped child; parents' need for support; views on their guidance needs in helping children develop; and preferences for school settings for their children. Parents' responses to each topic are summarized and charted according to five variables: type of handicap, residence (Hamilton, Waikato, or Auckland, New Zealand), age of child, socioeconomic status, and family size. Among major findings were that over half the parents were told about their child's problem within the first week, mostly by obstetricians and pediatricians; parents expressed the greatest need for information; and parents clearly preferred integrated school placements. (CL)

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'OTHER PEOPLE DON'T REALLY UNDERSTAND'

A SURVEY OF PARENTS OF CHILDREN WITH SPECIAL NEEDS

DAVID R. MITCHELL

OCCASIONAL PAPER NO.2

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ABSTRACT

This report presents the results of one of the studies carried out by members of Project PATH, a research project that was established at the University of Waikato in 1978. The present study was carried out in fulfillment of a contract with the Department of Education and with some additional funding provided by the IYC Telethon Trust.

The study examines the perceptions of 152 sets of parents of young children with special needs drawn from urban Auckland (60), urban Hamilton (40) and the smaller towns and country areas of the Waikato region (52). Data were obtained by means of structured interviews carried out with one or both parents in their own homes during the period 1978-80.

The independent variables employed in the study comprised place of residence (Auckland, Hamilton, Waikato), child's handicap (intellectual, physical, multi- and 'other'), child's age (under and over 48 months), socioeconomic status (high, low), child's age (under and over 48 months), and family size (1 or 2 children vs 3 or more).

Data are reported for the following variables: (a) telling parents they have a handicapped child (when they were first told, who told them, and which parent was first told); (b) parents' needs for support (needs for guidance and counselling, extent of support, and perceived value of meeting other parents); (c) parents' views on their guidance needs in helping their children in areas such as self care, language, behaviour management, and play activities and their reactions to attending parent training courses; (d) parents' familiarity and satisfaction with various professional groups and their awareness and use of various benefits and services; (e) parents' preferences for school settings for their children.

The results of the study are analysed and recommendations are presented in the context of relevant overseas and New Zealand studies of the families of handicapped children.

ACKNOWLEDGEMENTS

Many people and organisations contributed to the successful completion of this project:

Mrs Mary Lane was the principal investigator in the initial stages of the study, being responsible for designing the questionnaire and preparing the data for computer analysis.

Others to play a significant role in constructing and administering the questionnaire included Mrs Christine Hilton, Mrs Robyn Ward, Mrs Vivien Webb-Hendy, Mrs Jill Mitchell, Mrs Fenella Gill and Mr Doug MacLean.

Several students enrolled in the Diploma in Educational Guidance at the University of Waikato assisted in the administration of the questionnaire.

Dr Mark Topping contributed expert assistance in developing computer programmes for the data analysis.

Mrs Geraldine Keith and Mrs Val Lazenby were responsible for typing at various stages of the project.

The Crippled Children Society, the Society for the Intellectually Handicapped and the Psychological Service of the Department of Education assisted in the compilation of lists of potential subjects.

The Advisory Committee for Project PATH gave useful suggestions on the design of the questionnaire and on its administration.

The survey was funded by the Department of Education and by the IYC Telethon Trust.

The University of Waikato, in particular Professor Peter Freyberg, provided academic and material support for the project as a whole.

To all of the above individuals and organisations, I should like to record my gratitude. They played vital roles in what was a pleasing team effort.

Finally, I should like to acknowledge the willing participation of the parents who allowed us to intrude upon their privacy and who told us so freely about their child who is handicapped. It is my sincere wish that this report will go some way to ensure that the families of children with special needs receive the quality of services they have the right to expect from a modern society.

David Mitchell

DISSEMINATION

Progress reports on this study have been presented as follows:

The parent-professional partnership. Invited paper to the Paediatric Section of the XVIth Biennial Conference of the Australian Physiotherapy Association, Canberra, 1979. (Published in Paediatric Monograph of Australian Journal of Physiotherapy, 1979, 3-13).

Parents' perceptions of their guidance needs - a survey of parents of children with special needs. Paper presented at a Symposium on Mental Retardation, Psychology Section, ANZAAS, Auckland, 1979. (With M.M. Lane).

Project PATH - parents as teachers of the handicapped. In D.R. Mitchell (ed.) Papers from the 1st National Conference on Exceptional Children, Hamilton, 1980.

The perceptions parents of young handicapped children have of their guidance needs. Paediatric Society of New Zealand Annual Scientific Meeting, Auckland, 1980.

Parents - the untapped resource in special education. Set. Number two, item 10, 1981.

A survey of parents' experiences and views on being told they have a handicapped child. New Zealand Medical Journal, 1981, 94, in press.

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CHAPTER ONE

INTRODUCTION

I don't share details of my problems with people. You must not lean on people or expect help. You have a long-term problem that other people don't really understand.

1.1 Background to the study

In recent years, there has been a distinct trend in western societies for the handicapped to be maintained in their families and in the community, rather than being institutionalised (Annison and Young, 1980; Bayley, 1973; Bruininks et al, 1980; National Development Group for the Mentally Handicapped, 1977; New Zealand Society for the Intellectually Handicapped, 1979; Sax, 1980; Wilkin, 1978) and for the parents to accept considerable responsibility for actively undertaking training programmes with their handicapped children (Court, 1976; Parker and Mitchell, 1980). In tracing the history of this trend in New Zealand, Smith (1979) points out that although the full complexity of the problems of community care of the disabled have only presented themselves since the second world war, this philosophy had its origins in the nineteenth century. She attributed the recent emphasis on community care to such factors as the recognition that since more disabled persons are surviving and living longer they would place intolerable burdens on public hospitals, the emphasis from the behavioural sciences on maintaining disabled persons in their own homes, and the developments in medicine and technology which combine to provide the means to keep them in their homes.

In attempting to design appropriate models of service delivery to respond to these trends, researchers are increasingly studying what parents of handicapped children consider to be their needs and resources, as well as the ways in which they perceive their children and the quality of the services they have received from the various professions or agencies. Recent studies, for example, have focused on such issues as the way in which parents are told of their handicapped child's condition (e.g. Berg, Gilderdale and Way, 1969; Carr, 1970; Cunningham and Sloper, 1977; Gayton and Walker, 1974; Gilmore and Oates, 1972; Hallinan, 1978; Pueschel and Murphy, 1976; Pulman, 1979; Svarstad and Lipton, 1977), the effects of a handicapped child on family functioning (e.g. Birenbaum, 1971; Carr, 1975; Freeston, 1971; Gath, 1978; Hewett Newson and Newson, 1970; Lonsdale, 1978; Morrison, Beasley and Williamson, 1976; Reynolds, 1979; Salk, Hilgartner and Granich, 1972; Sommerville, Barnett and Malcolm, 1976), and parents' evaluations of services (e.g. Abramson et al,

1977; Bayley, 1973; Gath, 1978; Hallinan, 1978; Pulman, 1979; Walker, Thomas and Russell, 1971; Wilkin, 1979).

In the course of this report, a group of studies will be referred to on several occasions. It might be helpful, therefore, if these studies were described in broad outline at this juncture, with the detail of their findings being left to the appropriate sections of the report.

The study that most closely resembles the present one was carried out by Hallinan (1978). He surveyed a total of 94 families of young handicapped children in the Christchurch area. The children were mostly under the age of eight years and ranged across the spectrum of handicaps. Most of the parents were interviewed in their own homes, although a few completed postal questionnaires. Hallinan investigated a range of issues that included events surrounding parents being told they had a handicapped child, the nature of the support they received and their perceptions of various services.

A second New Zealand researcher to whose work frequent reference will be made is Pulman (1979(a), 1979(b)). In the first of her studies, Pulman carried out a mailed survey of the parents of 24 intellectually handicapped children who were enrolled in an early intervention project at Mangere Hospital and Training School. The questionnaire focused on the extent and quality of the medical services the families had received after the birth of the handicapped child. Pulman's second study interviewed the parents of 25 Down's Syndrome infants who had had some association with Mangere. Parents were interviewed mainly in areas to do with being told about their baby's condition and with the level and quality of the professional assistance they received.

Occasional reference will also be made to two other New Zealand studies - Morrison, Beasley and Williamson's (1976) nationally representative survey of the families of 2,245 intellectually handicapped persons under the age of 65, and Kuek and Laugeson's (1979) study of 53 cerebral palsied children in the Wellington area.

Gilmore and Oates (1977) interviewed the parents of 50 children with Down's Syndrone in New South Wales. A standard questionnaire used in the interviews sought information on such areas as the way in which parents were given the diagnosis, their utilisation of community resources, and the parents' attitudes to the information they were given.

The parents of 86 spina bifida children under the age of seven years comprised the subjects of a study carried out in Glasgow by Richards and McIntosh (1973). Interviews were conducted in the homes and covered topics such as sources of information and advice, attitudes to the child, the effect on the family and common problems.

Lonsdale (1978) has reported on the results of interviews of 60 families of handicapped children twelve years and younger. The main themes of the questionnaire were to do with how parents were told, their reactions, family stress, and the parents' opinions of support groups and counselling.

A large-scale study of the families of 180 cerebral palsied children under the age of nine was carried out by Hewett, Newson and Newson (1970) in the East-Midlands region. The topics of particular relevance to the present study included events surrounding being informed of the child's handicap, problems in behaviour management, and the parents' dealings with various statutory and voluntary agencies.

An even larger-scale survey was carried out by Bayley (1973) who investigated issues relating to 1,763 mildly and severely subnormal individuals in the Sheffield area. Within this study, he carried out an intensive investigation of a smaller sample of families. Although Bayley was concerned with the whole age range, there are sufficient data concerned with young children to warrant comparisons with the present study.

Carr (1975) interviewed the mothers of 54 Down's Syndrome infants born in the Surrey - London region, once when the children were fifteen months old and again when they were four years old. She was concerned at exploring problems encountered in such families and her results in such areas as behaviour management, being informed about handicap, self care, social support systems and the value of meeting other parents are particularly relevant to the present study.

The mothers of 120 severely mentally handicapped children in the Greater Manchester-Salford area were studied by Wilkin (1978). Themes covered in the home-administered questionnaire included the mothers' views on the help they received from other members of their family, from their social networks and from the various services, as well as their felt needs in helping their children.

In a second study carried out in the Greater Manchester area, Cunningham and Sloper (1977, 1979) interviewed the parents of 30 Down's Syndrome infants. The interviews were conducted in the homes and took place shortly after the parents had been informed of the diagnosis. The questions focused on such topics as when and how the parents were told, their reactions to the diagnosis and the extent to which they were helped to obtain access to further information.

1.2 Aims of the Study

The original contract with the Department of Education was "to survey and report on the perceptions of a group of parents of handicapped children of their own needs for guidance in teaching these children." After reviewing the literature and consulting with Project PATH's Advisory Committee and others, the following themes were selected for detailed study:

(a) when and how parents were first told of their child's condition;
(b) parents' needs for support, including their perceptions of the value of meeting other parents;
(c) parents' views of their guidance needs in aiding their child's development in such areas as self care, language and behaviour management;
(d) parents' familiarity and satisfaction with various professional groups and with the services and benefits to which they were entitled;
(e) parents' preferences for the school settings for their children.

CHAPTER TWO

RESEARCH METHODS

2.1 Subjects

The subjects for this study comprised 152 parents of children under the age of seven years and who had special needs[1]. In the first instance, voluntary organisations such as the Society for the Intellectually Handicapped and the Crippled Children Society and guidance services such as the Psychological Service of the Education Department were asked to nominate families in which there were children who fell into the age group and who had relatively "clear cut" handicaps such as Down's Syndrome, spina bifida, cerebral palsy, deafness or who were judged by professionals to have significant developmental delays. The parents of these children were then written to, explaining the survey's aims and seeking their participation in the study.

The survey proper was undertaken in two stages, the first in 1978 when 67 families in Hamilton and the smaller towns and rural areas of Waikato were interviewed and the second in 1979-80 when a further 25 families in those two areas and 60 families in urba- Auckland were interviewed. The final sample comprised 40 families in urban Hamilton, 52 in Waikato and 60 in Auckland (Table 1).

TABLE 1 : FAMILIES' PLACES OF RESIDENCE

Residence	N	%
Hamilton	40	26.3
Waikato	52	34.2
Auckland	60	39.5
Total	152	100.0

As can be seen in Table 2, parents of intellectually handicapped children made up the largest group (38.8 per cent), with 34.2 per cent being parents of physically handicapped children, 9.9 per cent parents of multi-handicapped children and 17.1 per cent parents of children with other handicaps such as deafness and non-specific developmental delay. Approximately 60 per cent of the children were 48-84 months of age, the other 40 per cent being under

[1] For ease of reference, the term "handicapped" will generally be employed in this report to refer to this group.

4? months of age (Table 3).

TABLE 2 : CHILDREN'S HANDICAPS

Handicap	Sub categories N	Sub categories %	Total N	Total %
Intellectual			59	38.8
Down's Syndrome	25	16.4		
Other	34	22.4		
Physical			59	34.2
Cerebral Palsy	28	18.4		
Other	24	15.8		
Multi-			15	9.9
Other[1]			26	17.1
Total			152	100.0

[1]Non-specific developmental delay, sensory handicap, uncategorised.

TABLE 3 : CHILDREN'S AGES

Age group	Sub categories N	Sub categories %	Total N	Total %
<48 months			60	39.5
>12 months	5	3.3		
12-23 months	20	13.2		
24-35 months	18	11.8		
36-47 months	17	11.2		
>48 months			92	60.5
48-59 months	31	20.4		
60-72 months	27	17.8		
>72 months	34	22.4		
Total			152	100.0

The socioeconomic status of the families was judged by the application of Elley and Irving's (1976) revised socioeconomic index for New Zealand - a scale which tends to be loaded more on the general dimension of vocational and educational achievements than on material circumstances (Fergusson and Horwood, 1979). In terms of the 1971 census data for New Zealand as a whole, on which this index is based, the present sample has a pronounced skew towards the higher socioeconomic levels (see Table 4). Whereas 55.3 per cent of the subjects were in the top three levels, Elley and Irving's corresponding figure for New Zealand was 40.3 per cent. This imbalance is almost identical to Hallinan's (1976) study, in which 54.3 per cent of the families were in the top three levels.

TABLE 4 : FAMILIES' SOCIOECONOMIC STATUS[1]

Socioeconomic group	Sub categories N	%	Total N	%
High			84	55.3
level 1	12	7.9		
level 2	20	13.2		
level 3	52	34.2		
Low			68	44.7
level 4	42	28.3		
level 5	22	14.5		
level 6	3	2.0		
Total			152	100.0

[1]Based on the application of Elley and Irving's scale to fathers' occupations, or to mothers' occupation in father-absent homes.

Just over half of the children were boys (53.3 per cent) - a proportion which tends to somewhat underestimate the preponderance of boys in the incidence of handicap (Braine et al, 1969; Mussen Conger and Kagan, 1979; Singer, Westphal and Niswander, 1968). As can be seen in Table 6, in approximately 60 per cent of the families the handicapped child was an only child or had one other sibling.

TABLE 5 : CHILDREN'S SEXES

Sex	N	%
Male	81	53.3
Female	71	46.7
Total	152	100.0

TABLE 6 : NUMBER OF CHILDREN IN FAMILIES

Number of children	Sub categories N	%	Total N	%
One or two			91	59.9
One	25	16.4		
Two	66	43.4		
Three or more			61	40.1
Three	33	21.7		
Four	16	10.5		
Five or more	12	7.9		
Total			151	100.0

With the exception of child's sex, all of these variables - place of residence, child's handicap, child's age, socioeconomic status, and the number of children in the family - were considered to be the independent variables of the study and were applied where appropriate. In order to establish that these variables

were not contaminated by each other, chi-square analyses of each in relation to the other were carried out. From Table 7 it can be seen that none of these comparisons achieved statistical significance and it can therefore be argued that each of the independent variables employed in the study are, in fact, relatively independent of each other.

TABLE 7 : CROSS-TABULATIONS OF INDEPENDENT VARIABLES

Independent variables	Number of categories	x^2	df	sig.
Residence	3			
X Socioeconomic status	2	3.32	2	NS
X Children's ages	2	2.84	2	NS
X Handicaps	4	2.06	6	NS
X No. of children in family	2	2.55	2	NS
Socioeconomic status	2			
X Children's ages	2	0.15	1	NS
X Handicaps	4	3.72	3	NS
X No. of children in family	2	0.32	1	NS
Children's ages	2			
X Handicaps	4	2.86	3	NS
X No. of children in family	2	0.50	1	NS
Handicaps	4			
X No. of children in family	2	2.00	3	NS

Table 8 summarises the data on the parents who were present at the interviews. In the case of the 137 two-parent families, both parents were present in 90 of the interviews and one parent (usually the mother) was present on 47 occasions.[1] The remaining 15 families - 9.9 per cent of the sample - were represented by solo parents (again, usually mothers). For some of the questions, separate data were recorded for fathers or mothers; in those cases, independence of judgement was ensured by the use of sets of cards which each parent placed in the order they saw fit. For those questions where no such comparisons were made and on the rare occasions when mothers and fathers differed in their opinions, only the mothers' responses were coded.

[1] This procedure of interviewing one or both parents in two-parent families has been used by other researchers (e.g. Cunningham and Sloper, 1977; Gilmore and Oates, 1977; Lonsdale, 1978, Pulman, 1979(b)).

TABLE 8 . : PARENT(S) PRESENT AT INTERVIEWS

Parent	N	%
Both parents	90	59.2
1 parent in 2 parent family	47	30.9
Solo parent	15	9.9
Total	152	100.0

2.2 Procedures

The data for this study were obtained by means of a two-hour structured interview carried out with one or both parents in their own homes. The interviews were focused on a 90-item questionnaire designed to elicit data on parents' perceptions of their guidance needs, the questions for which evolved from a review of the literature noted in the introduction and from consultations with a range of professionals associated with Project PATH. Parents of handicapped children who were not included in the final sample also assisted in the development of the questionnaire by evaluating its content and format, as well as providing useful suggestions for conducting the interviews. One couple consented to a videotaped interview which, together with a specially-prepared instruction manual, role plays and feedback opportunities, were used in training the interviewers. For the Hamilton and Waikato section of the study two two-hour training sessions were held for the interviewers who, in the main, comprised project members or senior students. In the case of the Auckland sample, the interviews were all carried out by a senior student who was herself the parent of a handicapped child. With the exception of the videotaped interview, the above procedures were followed in training this interviewer.

2.3 Statistical Analyses

Since the majority of the data obtained in the study are nominal or classificatory in character, the statistical significance of variations in the distribution of cases among categories is assessed by means of the non-parametric statistical test, chi-square (X^2) (Siegel, 1956). Qualitative data arising from comments made by parents in the course of the interviews will also be employed to illustrate trends in the data.

CHAPTER THREE

TELLING PARENTS THEY HAVE A HANDICAPPED CHILD[1]

He did not really explain it properly. He went round the point but never really explained it.

3.1 When Parents were First Told of their Child's Condition

From Table 9 it can be seen that one-fifth of the parents learned of their child's handicap at birth and a further one-fifth during the first month. By the time the child was 6 months of age one-half of the parents had become aware of the presence of a handicapping condition. Only 15 per cent of the sample were first told after the child turned two and none of the parents in the sample had been informed before birth of the possibility of a handicap. The present sample of families were first told of their child's condition slightly earlier than those in Hallinan's (1978) study. Examples of the differences include the following, Hallinan's data being noted in brackets: at birth : 20.4 per cent (11.6 per cent); by the end of the first month : 40.8 per cent (29.5 per cent); by the age of six months : 49.6 per cent (39.0 per cent). According to Laing and Jones (1979) 41 per cent of their sample of "mixed" handicaps (N = 145) under the age of five had conditions which were apparent at birth. It is not clear from their data, however, whether the diagnosis had been conveyed to the parents at birth.

TABLE 9 : WHEN PARENTS WERE FIRST TOLD OF CHILD'S CONDITION[1]

Before birth	N	%	Cumulative %
Before birth	0	0.0	0.0
At birth	30	20.4	20.4
In first week	24	16.3	36.7
In first month	6	4.1	40.8
In first six months	13	8.8	49.6
In first year	28	19.1	68.7
In first 2 years	24	16.3	85.0
In 2-5 years	19	12.9	97.9
In 5-7 years	3	2.0	99.9
Total	147	100.0	

[1]Five parents indicated that they were not sure, never told, or that it was a process of gradual awareness.

[1]Parts of this chapter were published in the following article: Mitchell, D.R. A survey of parents' experiences and views on being told they have a handicapped child. New Zealand Medical Journal, in press.

The point at which parents were first told of their child's condition differed according to the nature of the child's handicap (Table 10). Just over half of those with an intellectual handicap were detected in the first month, compared with around one-third of the physically and multi-handicapped and only one-fifth of the 'other' categories (i.e., non-specific developmental delay, sensory handicap and uncategorised). The differences in the distribution in this table were statistically significant (X^2 = 13.59, 6 df, p<.05).

TABLE 10 : WHEN PARENTS WERE FIRST TOLD OF CHILD'S CONDITION, BY HANDICAP

Handicap	Within first month		Within first year		Within first 7 years		Total	
	N	%	N	%	N	%	N	%
Intellectual	31	*53.5*	14	*24.1*	13	*22.4*	58	*100.0*
Physical	19	*37.3*	17	*33.3*	15	*29.4*	51	*100.0*
Multi-	5	*35.7*	5	*35.7*	4	*28.6*	14	*100.0*
Other	5	*20.8*	5	*20.8*	14	*58.3*	24	*100.0*
All	60	*40.8*	41	*27.9*	46	*31.3*	147	*100.0*

X^2 = 13.59, 6 df, p <.05

When separate analyses are carried out for the 25 families with Down's Syndrome children, 84.0 per cent of the parents were first told of the condition in the first week. This figure is comparable to Pulman's (1979(b)) 88.0 per cent, Gilmore and Oates's (1977) 72.0 per cent and Cunningham and Sloper's (1977) 66.7 per cent, and is considerably in excess of Gayton and Walker's (1974) 59.0 per cent, Berg, Gilderdale and Way's (1969) 56.9 per cent, Pueschel and Murphy's (1976) 56.3 per cent, Gath's (1978) figure of 46.7 per cent, Carr's (1970, 1975) 41.3 per cent and Drillien and Wilkinson's (1964) 21.5 per cent. These data indicate an increasing trend for parents to be informed earlier of their child's Down's Syndrome, a tendency that probably reflects the technical advances in being able to make quick, firm diagnoses. It may also indicate a preparedness on the part of the medical profession to convey this information to parents as soon as possible - which is in line with parents' own preferences (Berg, Gilderdale and Way, 1969; Carr, 1970; Cunningham, 1979; Cunningham and Sloper, 1977; Gilmore and Oates, 1977; Wilson, 1975).

3.2 Who Told Parents of their Child's Condition

From Table 11 it is clear that the medical profession and allied health services bear the brunt of informing parents of the presence of a handicapping condition in their child. Medical specialists such as obstetricians and paediatricians have the main responsibility in this respect, with 69.0 per cent of parents reporting that they were first told by such a person, the next largest group being family doctors with 16.6 per cent, followed by nursing and other hospital staff (9.7 per cent).

This pattern is very similar to that reported by Hallinan (1978) in his Christchurch survey, the comparable percentages for the above categories being 62.9, 19.1 and 3.4, respectively. It is similar, too, to American data in which 66.7 per cent of mothers of Down's Syndrome children had been informed by a paediatrician or obstetrician and 22.8 per cent by the family doctor (Pueschel and Murphy, 1976), and to Richards and McIntosh's (1973) finding that in 71 per cent of the cases of spina bifida a midwife or hospital doctor had conveyed the first information to the mother, compared with 13 per cent for general practitioners.

TABLE 11 : PERSON WHO FIRST TOLD PARENTS OF CHILD'S CONDITION[1]

Medical specialist		General practitioner		Nurse/other hosp. staff		Plunket/ PHN		Other		Total	
N	%	N	%	N	%	N	%	N	%	N	%
100	*69.0*	24	*16.6*	14	*9.7*	3	*2.1*	4	*2.8*	145	*100.0*

[1] Six parents had never been clearly told by any one person.

3.3 Which Parent was First Told

Table 12 summarises the data from two-parent families relating to which parent was first told of their child's condition. In 45.7 per cent of the cases, both parents were told together. Of the remaining 54.3 per cent, the mothers had been told alone in 44.2 per cent of the cases and the father on 10.1 per cent. This pattern was consistent across the various sub-groups that were yielded by the five independent variables. The proportion of families in which both parents were told together is almost identical to that reported by Hallinan (1978) but higher than in Lonsdale's (1978) survey in which only 28.1 per cent of the mothers and 32.8 per cent of the fathers were told with their spouse.

TABLE 12 : PARENT WHO WAS FIRST TOLD OF CHILD'S CONDITION[1]

Independent variable	Both parents together		One parent alone[2]		Total	
	N	%	N	%	N	%
All families	59	45.7	70	54.3	129	100.0
Handicap						
Intellectual	21	40.4	31	59.6	52	100.0
Physical	19	43.2	25	56.8	44	100.0
Multi-	9	60.0	6	40.0	15	100.0
Other	10	55.6	8	44.4	18	100.0
x^2 = 2.65, 3 df, NS						
Residence						
Hamilton	10	34.5	19	65.5	29	100.0
Waikato	24	54.6	20	45.4	44	100.0
Auckland	25	44.6	31	55.4	56	100.0
x^2 = 2.88, 2 df, NS						
Age						
<48 months	24	43.6	31	56.4	55	100.0
>48 months	35	47.3	39	52.7	74	100.0
x^2 = 0.17, 1 df, NS						
Socioeconomic status						
High	37	48.7	39	51.3	76	100.0
Low	22	41.5	31	58.5	53	100.0
x^2 = 0.65, 1 df, NS						
Family size						
1 or 2 chn.	35	47.3	39	43.2	74	100.0
3 or more chn.	24	43.6	31	45.5	55	100.0
x^2 = 0.17, 1 df, NS						

[1] For 21 families, this question was not applicable either because it was a solo parent family or the parents were never told or there was a process of gradual awareness.

[2] Mother alone (57) father alone (13)

When the data on this variable are analysed with respect to the families of Down's Syndrome, however, in only 32.0 per cent of the cases had parents been told together, while mothers had been told alone in 48.0 per cent of the cases and fathers in 12.0 per cent. This pattern is very similar to other studies of families of Down's Syndrome children. Taking the proportion of families where both parents had been told together, the range was from 20 per cent (Gilmore and Oates, 1977) to 40 per cent (Pulman, 1979(b)), with several studies reporting figures of around 25-30 per cent (Carr, 1970, 1975; Cunningham and Sloper, 1977; Gayton and Walker, 1974).

As summarised in Table 13, of the 70 families where one of the parents had been first told alone of their child's condition, 44 (62.9 per cent) had a distinct preference in retrospect for being told together. Of the remaining 36 families, 19 continued to prefer not being told together and 7 were unsure. There were no significant variations in this pattern of preferences when the five independent variables of child's handicap, residence, child's age, socioeconimic status, and family size were taken into account.

TABLE 13 : PARENTS' PREFERENCES FOR BEING TOLD TOGETHER OR ALONE[1]

Independent variable	Prefer to be told together		Prefer not to be told together/ unsure[3]		Total	
	N	%	N	%	N	%
All families	44	62.9	26	37.1	70	100.0
Handicap						
Intellectual	21	70.0	9	30.0	30	100.0
Physical	15	62.5	9	37.5	24	100.0
Other[2]	8	50.0	8	50.0	16	100.0
x^2 = 1.79, 2 df, NS						
Residence						
Hamilton	9	47.4	10	52.7	19	100.0
Waikato	15	68.2	7	31.9	22	100.0
Auckland	20	69.0	9	31.0	29	100.0
x^2 = 2.68, 2 df, NS						
Age						
<48 months	22	75.9	7	24.1	29	100.0
>48 months	22	53.7	19	46.3	41	100.0
x^2 = 2.70, 1 df, NS						
Socioeconomic status						
High	21	55.3	17	44.7	38	100.0
Low	23	71.9	9	28.1	32	100.0
x^2 = 1.40, 1 df, NS						
Family size						
1 or 2 chn.	27	69.2	12	30.8	39	100.0
3 or more chn.	17	54.8	14	45.2	31	100.0
x^2 = 1.53, 1 df, NS						

[1] Question asked only of respondents where one of parents had been told alone (see Table 3.4).

[2] Includes 6 multi-handicapped.

[3] Prefer not to be told together (19), unsure (7).

The general preference for being told together is in accord with the findings of other studies (Cunningham and Sloper, 1977; Gayton and Walker, 1974; Hallinan,

1978; Lonsdale, 1978; Pulman, 1979(b); Wilson, 1975). The presence of a significant minority who prefer one parent to be told first, however, should not be overlooked - a factor which along with a variety of others (Webb-Hendy and Mitchell, 1981), should be taken into account when decisions are made as to the way in which parents should be informed.

3.4 How Parents were Informed

Although no systematic attempt was made to evaluate other more qualitative aspects of how parents had been informed that their child was handicapped, many parents raised important issues when they were asked, 'At the time you were first told, was anything done or said which was really not helpful for you?" Since obstetricians, paediatricians and general practitioners bear the main responsibility for informing parents, most of the comments elicited by this question refer to the medical profession. It must be noted, too, that although the bulk of the comments selected for inclusion are negative in tone, many parents had very positive feelings towards the professions with whom they had contact (see Chapter Six).

In the main, the comments focused on three themes - information about the child's condition, information about how to help the child and the quality of the parent-professional relationship.

3.4.1 Information about the child's condition.

Parents complained about several features to do with the quality of the information conveyed to them by the professionals with whom they came into contact during or after being informed of their child's condition.

Some felt that the professionals simply did not know enough about their child's handicap:

> *The doctor was ignorant. He said it was hereditory, but it was trisomy 21. (136)*[1]
>
> *The medical social worker was dumb - ignorant of Down's Syndrome - and gave us unhelpful and misleading advice. (108)*
>
> *A sister in the hospital gave me misleading information on heredity. (015)*

Others pointed out the problems they experienced in understanding professionals:

> *He did not really explain it properly. He went round the point but never really explained it. (092)*

---

[1] Numbers refer to individual families.

The paediatrician is a hard man to understand. He explains it in big medical words. (049)

There was terrible initial waffling. - I would have preferred specific information - especially specific diagnosis and progress. I was in a limbo of disbelief. This 'wait and see' attitude by professionals is very difficult to endure. (103)

The lack of coordination among specialists came in for criticism by some of the parents:

We were given conflicting information by different people. (115)

Eventually, at 3 months, I was told ___ has suffered a cerebral haemorrhage at birth. My doctor thought the paediatrician had told me this when they had found out, and the paediatrician thought the doctor had told me. Neither of them checked, so it was assumed we knew. (097)

Professional brusqueness annoyed some parents:

The doctor would not seem to try and understand how normal _____ had been before the virus. He implied that _____ would have been born like this - even though it did not show until she was three. (038)

The psychologist spent half an hour and made brash statements. He assessed her without looking at her. (002)

Doctors don't take enough time to assess her. (001)

At 2½ years I saw a psychologist and he said straight out she was IH and wouldn't develop over 12 months ever. I never went back to him. (024)

3.4.2 Information about how to help the child. Some parents felt that they had been given insufficient or inadequate advice on how they might best help their child's development:

We saw the doctor at __ Hospital four days later. She painted a very gloomy and pessimistic picture. She didn't know what was available. We had to do all the finding out ourselves. (149)

I would have liked to have been told the alternatives, but the paediatrician wasn't conversant with what was available. (109)

The only book they could produce from the Hospital Library on Down's Syndrome was published in 1957. (054)

The paediatrician said don't rush to Mangere or join IHC. This delayed help for ___ until she was a year old. I wasted a year. (129)

The psychologist gave no advice at all. He said he would get back to me, but he didn't give me any information. (094)

3.4.3 The quality of the parent-professional relationship. Many parents commented on what they perceived to be deficiencies in the interpersonal skills of professionals who broke the news of their child's handicap to them. The problems they encountered fell into two main categories:

Firstly, some parents experienced insensitivity to their feelings:

The first paediatrician was blunt - no humanity. I felt obliged to be very careful phrasing my questions so as not to upset him. But a mother

who has given birth to an abnormal baby should be kindly treated. She should be treated with care and more as a person - a person shocked and upset ... we went privately to another paediatrician who told us what he was testing for and answered our questions. (144)

The way the paediatrician broke the news - he was abrupt and distant. He stood in the doorway and told the nurse to go and settle the lady (me - who was crying). (159)

A week after the birth, this doctor - who was very young - gave me the test results with four or five other doctors around the bed. I was terribly upset. I didn't think he had the right. (142)

I was mostly upset by the offhand uncaring manner of the specialist and our own family doctor. (062)

Secondly, some parents were critical at the lack of openness from professionals:

Being by myself, the paediatrician was hard to talk to. Couldn't ask much I was so flabbergasted. But when I did ask, he just answered, 'It's cerebral palsy'. (075)

The neurosurgeon was negative, discouraging, gave us no hope, said the child would not live - Suddenly said child could go home and never admitted his prognosis was wrong. (145)

The gynaecologist knew there was a 50/50 chance of retardation from birth, but did not tell me this for months. (127)

The specialist made me feel I was just the bearer of the child. He was not straightforward. My husband often got more from the specialist if I left the room. (040)

3.5 Recommendations

Arising from the quantitative and qualitative data obtained in this aspect of the study, the following recommendations are advanced:

1. Given the concerns expressed by many parents regarding the way in which professionals informed them about their child's handicap, it is recommended:

   (a) That the training programmes of the various professions likely to be involved in informing parents of the presence of handicapping conditions in their children include significant components of relevance to this aspect of their work. In particular, there should be reference to recent advances in the medical, educational and community provisions for handicapped children and to the need for sensitivity in interactions with the parents of handicapped children (Mittler, 1979; Spain and Wigley, 1975).

   (b) That since the medical profession bears the main responsibility for informing parents of their child's handicap, the above recommendation be accepted as a high priority by those responsible for

designing medical education courses at both the under- and post-graduate levels, and that individual professionals accept their personal responsibility for becoming better informed and more skilled in this area (Gayton, 1975; Jacobs, 1971; Lipton and Svarstad, 1977; Sanson-Fisher and Maguire, 1980; Wahlstrom and Sterner, 1978; Wolraich and Reiter, 1979).

2. That professionals who are confronted with the responsibility of informing, or confirming to, parents that their child has a handicapping condition recognise that the majority of parents would prefer to be told with their spouse. They should recognise, however, that since a significant minority of parents would prefer to be told alone, the dynamics of each individual family should be considered when deciding how their responsibility is discharged - if, indeed, it is possible to exercise any control over it.

CHAPTER FOUR

PARENTS' NEEDS FOR SUPPORT

I get lots of kindly, supportive concern. They're caring and sorry but it goes no further. There isn't the amount of practical help I'd like.

4.1 Needs for Guidance and Counselling

Subjects in the 1979-80 phase of the study were asked to comment on the extent to which their needs for guidance and counselling had been met. Table 14 shows that in terms of proportion of parents who experienced particular needs but considered that these were not being satisfied, the most pressing was for further information regarding their child's handicap and what they could do to help (59.0 per cent). This was followed by a closely allied need for good reading material (36.1 per cent) and then a bracket of three needs each attracted 25 per cent of the respondents (help with practical difficulties, encouragement to return for guidance and for counselling for reactions and feelings). In considering the support from family and friends, the bulk of the parents felt that their needs had been satisfied (54.2 per cent) or that they had not experienced the need for such support (28.9 per cent).

TABLE 14 : PARENTS' VIEWS OF THE EXTENT TO WHICH THEIR NEEDS FOR GUIDANCE AND COUNSELLING HAVE BEEN MET[1]

Type of help	Experienced need: Satisfied N	Satisfied %	Not satisfied N	Not satisfied %	No need N	No need %	Total N	Total %
More information	17	20.5	49	59.0	17	20.5	83	100.0
Good reading material	11	13.2	30	36.1	42	50.6	83	100.0
Help with practical difficulties	5	6.0	22	26.5	56	67.5	83	100.0
Encouragement to return for guidance	28	33.7	21	25.3	34	41.0	83	100.0
Counselling for reactions and feelings	4	4.8	21	26.3	58	69.9	83	100.0
Support from family and friends	45	54.2	14	16.9	24	28.9	83	100.0

[1] 1979-80 data only

The clear picture that emerges from this and other studies is that parents want a good deal more information on their child's handicap and what they can do to ameliorate it than is presently being provided. The 79.5 per cent of the present sample who experienced the need for information is comparable to

the 68.8 per cent of Hallinan's (1978) sample who wanted information on their child's primary disability, the 72 per cent of Pulman's (1979(b)) subjects who felt the need for more guidance after the initial interviews and the 64 per cent of Gilmore and Oates' (1977) parents in N.S.W. who wanted early contact with facilities. Although they presented no data, Goddard and Raynor (1978) reported that their sample of parents in Exeter repeatedly raised the need for follow-up consultations to discuss the diagnosis and its implications. Despite this need, the evidence suggests that it is not fully being met, Cunningham and Sloper (1977), for example, reporting that nearly half of their sample of parents in the Manchester region left hospital with vital questions unanswered.

The comparatively low values placed upon counselling and on further support from family and friends suggests that, on the whole, the parents in the present sample have come to terms with the emotional implications of a handicapped child in the family. This finding stands in contrast with the results of a survey of professionals in the Hamilton - Waikato area in which 65.5 per cent of the respondents emphasised the need for professional support and counselling of parents. The notion that parents of handicapped are generally adaptive and not pathological in their reactions is given credence in other studies, too. Hallinan (1977, p.202), for example, considered that for the overwhelming majority of the parents in his sample, "the primary reaction was one of rationale adjustment", while Svarstad and Lipton (1977, p.651) concluded from their study of professional communication with parents of mentally retarded children that "there has been too much emphasis on the parents' psychological problems and not enough on how professionals inform parents".

4.2 Sources and Extent of Support

Parents were asked to identify the sources of support or help of any kind they had received and were shown a list which included such categories as husband/wife, other relatives, medical people, close personal friends, neighbours, voluntary organisations, personal faith, clergy, etc. Table 15 shows the distribution of the parents in terms of the number of different categories of support they identified. Less than 10 per cent of them noted no sources or one source, while just over 60 per cent identified four or more.

TABLE 15 : SOURCES OF SUPPORT IDENTIFIED BY PARENTS

None		One		Two or three		Four to six		More than six		Total	
N	%	N	%	N	%	N	%	N	%	N	%
2	*1.3*	11	*7.3*	45	*30.0*	67	*44.7*	25	*16.7*	150	*100.0*

The parents' views on the extent to which they currently have sufficient support of the kind they needed from family and friends are summarised in Table 16[1]. Nearly half of the sample (48.2 per cent) considered they currently had sufficient support, while just over one fifth (21.2 per cent) thought they had insufficient support. A large group of the parents expressed ambivalence, mainly because of differences in the extent and quality of the support they received currently and when their handicapped child was younger.

Although the differences between parents of the younger and older children on this variable were not statistically significant, the data were pointing in the direction of the former group feeling that they had insufficient support. Certainly, some of the parents made comments along these lines:

> *We needed it desperately early on - especially emotional encouragement and hope. We don't need it as much now. (115)*
>
> *We struggled by ourselves at the beginning. We needed it then, but now we don't need it as much. (117)*
>
> *I needed another adult to help me cope, to get me through my days - someone who understood all these things and could help me in the early stages.*

The finding that nearly half of the parents felt they had sufficient support is comparable to Carr's (1975) research in which just over half of the mothers of her sample of mothers of Down's Syndrome infants said that they received "some" or "much" support from relatives or friends, and to Bayley's (1973, p.282) opinion that 54.7 per cent of his sample of 53 families received "good" levels of support, compared with 20.8 per cent who received "shaky" support and 24.5 per cent also received "poor" support.

It must be conceded, however, that the general findings reported in the present study and the others just cited may not be a fair reflection of what actual

[1] If one parent said 'yes' and the other 'no' the response was coded as 'no'.

support or help is received by parents. For example, when Wilkin (1979, p.140) questioned his sample of parents to determine instances of help, he found that when evaluated against the day-to-day practical burdens of families, "the impact of community was negligible for most".

TABLE 16 : PARENTS' VIEWS OF THE EXTENT TO WHICH THEY CURRENTLY HAVE SUFFICIENT SUPPORT[1]

Independent variable	Sufficient support Yes		Ambivalent[2]		Insufficient support		Total	
	N	%	N	%	N	%	N	%
All families	41	48.2	26	30.6	18	21.2	85	100.0
Handicap								
Intellectual	14	45.2	11	35.5	6	19.4	31	100.0
Physical	17	56.7	7	23.3	6	20.0	30	100.0
Multi-	3	30.0	4	40.0	3	30.0	10	100.0
Other	7	50.0	4	28.6	3	21.4	14	100.0
x^2 = 2.70, 6 df, NS								
Residence								
Hamilton	11	44.0	10	40.0	4	16.0	25	100.0
Auckland	30	50.0	16	26.7	14	23.3	60	100.0
x^2 = 1.61, 2 df, NS								
Age								
<48 months	15	44.1	8	23.5	11	32.4	34	100.0
>48 months	26	51.0	18	35.3	7	13.7	51	100.0
x^2 = 4.46, 2 df, NS								
Socioeconomic status								
High	22	47.8	17	37.0	7	15.2	46	100.0
Low	19	48.7	9	23.1	11	28.2	39	100.0
x^2 = 3.01, 2 df, NS								
Family size								
1 or 2 chn.	29	54.7	14	26.4	10	18.9	53	100.0
3 or more chn.	12	37.5	12	37.5	8	25.0	32	100.0
x^2 = 2.38, 2 df, NS								

[1] 1979-80 data only

[2] Differences between earlier and current support

4.3 Value of Meeting Other Parents

Data on the parents' views on the value of meeting parents of children with similar handicaps are included in Table 17. Overall, three-quarters of those in the sample had met other parents, the vast majority of these respondents considering the contacts to be of value, a pattern similar to that reported by

Carr (1975). There were some variations from group to group when the various independent variables were applied to the sample, but none of them reached statistical significance. In other words, the pattern of preference for meeting parents of similarly handicapped children was present irrespective of the child's handicap, place of residence, child's age, father's socioeconomic status and family size. Although not recorded in Table 17, it is worth noting that a similar preference was expressed by those who had not met other parents, the 25.8 per cent in this category being made up of 20.5 per cent who would like to and only 5.3 per cent who did not want to meet other parents of handicapped children. In other words, 84.1 per cent of the parents had either met other parents and considered it of value or would like to meet other parents if they had not already done so.

TABLE 17 : PARENTS' VIEWS ON VALUE OF MEETING PARENTS OF CHILDREN WITH SIMILAR HANDICAPS

Independent variable	Have met other parents: Considered it of value N	%	Considered it of little/no value N	%	Have not met other parents[1] N	%	Total N	%
All families	96	63.6	16	10.6	39	25.8	151	100.0
Handicap								
Intellectual	39	66.1	6	10.2	14	23.7	59	100.0
Physical	28	53.8	6	11.5	18	34.6	52	100.0
Multi-	10	66.7	3	20.0	2	13.3	15	100.0
Other	19	76.0	1	4.0	5	20.0	25	100.0
x^2 = 6.69, 6 df, NS								
Residence								
Hamilton	24	60.0	4	10.0	12	30.0	40	100.0
Waikato	29	56.9	5	9.8	17	33.3	51	100.0
Auckland	43	71.7	7	11.7	10	16.7	60	100.0
x^2 = 4.50, 4 df, NS								
Age								
<48 months	41	68.3	8	13.3	11	18.9	60	100.0
>48 months	55	60.4	8	8.8	28	30.8	91	100.0
x^2 = 3.22, 2 df, NS								
Socioeconomic status								
High	55	65.5	6	7.1	23	27.4	84	100.0
Low	41	61.2	10	14.9	16	23.9	67	100.0
x^2 = 2.42, 2 df, NS								
Family size								
1 or 2 chn.	62	68.1	10	11.0	19	20.9	91	100.0
3 or more chn.	34	56.7	6	10.0	20	15.3	60	100.0
x^2 = 2.95, 2 df, NS								

[1] Would like to (31), do not want to (8).

4.4 Recommendations

In the light of the above data on parents' perceptions of their needs for support, the following recommendations are made:

1. That all professionals who have contact with handicapped children be provided with regular updated reading lists relating to various handicaps.

2. That directories of services relating to the needs of families of young children with handicaps be compiled for every region within New Zealand (for example, see a handbook compiled by the Waikato Branch, NZ Federation of University Women, 1979).

3. That handbooks on handicap written for parents be made widely available (for example, see Mitchell, 1979, and a recent review of such books by Smith, 1981).

4. That regional resource centres be established to provide an information service to professionals and parents concerned with young handicapped children (Dean, 1975; Threlfall, 1979).

5. That statutory agencies such as the Health and Education Departments and voluntary bodies concerned with handicap collaborate in the provision of the above services.

6. That professionals working with parents of handicapped children immediately following their being informed of their child's condition should take account of the emotional impact of such information on the whole family and

   (a) arrange for parents to return for several interviews in order to clarify their understanding and to come to terms with their feelings;

   (b) help the parents to make contact with parents of children with similar handicaps (Hornby, 1980), and

   (c) ensure that some single person has responsibility for coordinating contacts with professionals and others (Mittler, 1979; Spain and Wigley, 1975; Warnock, 1978).

CHAPTER FIVE

PARENTS' VIEWS ON THEIR GUIDANCE NEEDS

I would go to courses if they were relevant and specific to my child.

5.1 Self Care

The parents were questioned regarding their desire to know more about ways of helping their children learn the self care skills of feeding, toileting, dressing and washing. From Table 18, it can be seen that 25.5 per cent of the parents wanted guidance in three or four of these areas and another 38.9 per cent in one or two areas, while the remaining 35.6 per cent felt no need for guidance in any of the areas. Although there were some variations in this distribution on the various independent variables, none of them were statistically significant.

TABLE 18 : PARENTS' WISHES TO KNOW MORE ABOUT HELPING THEIR CHILDREN LEARN SELF CARE SKILLS

Independent variable	Yes for 3 or 4 areas		Yes for 1 or 2 areas		No for all areas		Total	
	N	%	N	%	N	%	N	%
All families	38	25.5	58	38.9	53	35.6	149	100.0
Handicap								
Intellectual	16	28.1	20	35.1	21	36.8	57	100.0
Physical	10	19.2	22	42.3	20	38.5	52	100.0
Multi-	5	33.3	7	46.7	3	20.0	15	100.0
Other	7	28.0	9	36.0	9	36.0	25	100.0
χ^2 = 3.20, 6 df, NS								
Residence								
Hamilton	16	41.0	13	33.3	10	25.6	39	100.0
Waikato	10	19.2	18	34.6	24	46.2	52	100.0
Auckland	12	20.7	27	46.6	19	32.8	58	100.0
χ^2 = 9.21, 4 df, NS								
Age								
<48 months	13	21.7	27	45.0	20	33.3	60	100.0
>48 months	25	28.1	31	34.8	33	37.1	89	100.0
χ^2 = 1.67, 2 df, NS								
Socioeconomic status								
High	25	30.5	34	41.5	23	28.0	82	100.0
Low	13	19.4	24	35.8	30	44.8	67	100.0
χ^2 = 4.98, 2 df, NS								
Family size								
1 or 2 chn.	21	23.6	35	39.3	33	37.1	89	100.0
3 or more chn.	17	28.3	23	38.3	20	33.3	60	100.0
χ^2 = 0.47, 2 df, NS								

Table 18A shows that the percentage of parents who wanted to know more about helping their children in the particular self care areas ranged from 43.6 per cent for feeding to 26.5 per cent for washing. The figures in Table 18A held up across all of the independent variables except in the case of dressing where a higher proportion of high socioeconomic status parents (45.1 per cent) than of lower socioeconomic status parents (23.1 per cent) wanted to know more about how to help their children ($X^2 = 7.71$, 1 df, $p<.01$).

TABLE 18A : PARENTS' WISHES TO KNOW MORE ABOUT HELPING THEIR CHILDREN LEARN FEEDING, TOILETING AND DRESSING SKILLS

	Yes		No		Total	
Self Care Area	N	%	N	%	N	%
Feeding	65	43.6	84	56.4	149	100.0
Toileting	58	39.5	89	60.5	147	100.0
Dressing	52	35.4	95	64.6	147	100.0
Cleanliness & Grooming	39	26.5	108	73.5	147	100.0

Of the 100 parents who had received some guidance in helping their children learn self care skills, 78 per cent had found it to be helpful, 13 per cent had assigned it a neutral value and 9 per cent a negative value (Table 19). A higher proportion of the Auckland parents, compared with those from Hamilton and Waikato, had both tried guidance and found it to be helpful.

The proportion of parents who felt they wanted to know more about helping their children learn the various self care skills was rather higher than that reported by Wilkin (1979) in his survey of families with a severely mentally handicapped child. For example, whereas 43.6 per cent of the parents in the present study expressed the need for guidance in feeding, only 9 per cent of Wilkin 's families who actually had children with feeding difficulties wanted more help. These differences can probably be accounted for by the fact that whereas in the current investigation the parents were asked if they wanted guidance, Wilkins asked his parents about their needs for further practical assistance. No other study that has addressed this issue in a manner comparable to this one could be found in the literature.

TABLE 19 : PARENTS' VIEWS OF VALUE OF GUIDANCE IN HELPING THEIR CHILDREN LEARN SELF CARE SKILLS

Independent variable	Felt no need of guidance		Tried guidance: Helpful value		Tried guidance: Neutral/ negative[1] value		No guidance would have liked some		Total	
	N	%	N	%	N	%	N	%	N	%
All families	27	18.4	78	53.1	22	15.0	20	13.6	147	100.0
Handicap										
Intellectual	11	19.3	27	47.4	8	14.1	11	19.3	57	100.0
Physical	10	19.6	29	56.9	6	11.8	6	11.8	51	100.0
Multi-	2	13.3	12	80.0	1	6.7	0	0.0	15	100.0
Other	4	16.7	10	41.7	7	29.2	3	12.5	24	100.0
x^2 = 11.29, 9 df, NS										
Residence										
Hamilton	10	25.6	19	48.7	4	10.3	6	15.4	39	100.0
Waikato	14	28.0	20	40.0	9	18.0	7	14.0	50	100.0
Auckland	3	5.2	39	67.2	9	15.5	7	12.1	58	100.0
x^2 = 14.19, 6 df, P<.05										
Age										
<48 months	12	20.3	34	57.6	10	17.0	3	5.1	59	100.0
>48 months	15	17.0	44	50.0	12	13.6	17	19.3	88	100.0
x^2 = 6.11, 3 df, NS										
Socioeconomic status										
High	15	18.3	43	52.4	14	17.0	10	12.2	82	100.0
Low	12	18.5	35	53.8	8	12.3	10	15.4	65	100.0
x^2 = 0.84, 3 df, NS										
Family size										
1 or 2 chn.	15	17.0	48	54.5	17	19.3	8	9.1	88	100.0
3 or more chn.	12	20.3	30	50.8	5	8.5	12	20.3	59	100.0
x^2 = 6.36, 3 df, NS										

[1] 8.8% neutral and 6.1% negative value.

5.2 Language

Table 19 shows that nearly two-thirds of the parents (62.3 per cent) expressed the wish to know more about how to help their children's language development - a figure lower for parents in the Auckland area (45.0 per cent) than for those in Hamilton (73.0 per cent) and Waikato (75.5 per cent). Although there was a trend towards parents of children whose language was at the vocalisation/single word stage to want more guidance than parents of children who were able to put two or more words together, the differences failed to achieve statistical significance (x^2 = 2.50, 1 df).

TABLE 20 : PARENTS' WISHES TO KNOW MORE ABOUT HELPING THEIR CHILDRENS' LANGUAGE DEVELOPMENT

Independent variable	Wish to know more		No wish to know more		Total	
	N	%	N	%	N	%
All families	91	62.3	55	37.7	146	100.0
Handicap						
Intellectual	41	71.9	16	28.1	57	100.0
Physical	25	50.0	25	50.0	50	100.0
Multi-	11	73.3	4	26.7	15	100.0
Other	14	58.3	10	41.7	24	100.0
x^2 = 6.41, 3 df, NS						
Residence						
Hamilton	27	73.0	10	27.0	37	100.0
Waikato	37	75.5	12	24.5	49	100.0
Auckland	27	45.0	33	55.0	60	100.0
x^2 = 13.09, 2 df, p<.01						
Age						
<48 months	34	58.6	24	41.3	58	100.0
>48 months	57	64.8	31	35.2	88	100.0
x^2 = 0.56, 1 df, NS						
Socioeconomic status						
High	52	65.8	27	34.2	79	100.0
Low	39	58.2	28	41.8	67	100.0
x^2 = 0.90, 1 df, NS						
Family size						
1 or 2 chn.	53	60.9	34	39.1	87	100.0
3 or more chn.	38	64.4	21	35.6	59	100.0
x^2 = 0.18, 1 df, NS						
Stage of Language						
Vocalises/single words	47	69.1	21	30.9	68	100.0
Puts 2 or more words together	44	56.4	34	43.6	78	100.0
x^2 = 2.50, 1 df, NS						

5.3 Behaviour Management

Table 21 shows that just over half of the parents (54.4 per cent) expressed the wish for guidance in managing their children's behaviour, with a significantly higher proportion of 'other handicaps' (80.5 per cent) and parents living in Hamilton (71.1 per cent) expressing such a need.

TABLE 21 : PARENTS' WISHES FOR GUIDANCE IN MANAGING THEIR CHILDRENS' BEHAVIOUR

Independent variable	Yes		No		Total	
	N	%	N	%	N	%
All families	80	54.4	67	45.6	147	100.0
Handicap						
Intellectual	28	48.3	30	51.7	58	100.0
Physical	24	49.0	25	51.0	49	100.0
Multi-	7	50.0	7	50.0	14	100.0
Other	21	80.8	5	19.2	26	100.0
x^2 = 8.86, 3 df, p<.05						
Residence						
Hamilton	27	71.1	11	29.0	38	100.0
Waikato	27	54.0	23	46.0	50	100.0
Auckland	26	44.1	33	55.9	59	100.0
x^2 = 6.79, 2 df, p<.05						
Age						
<48 months	27	47.4	30	52.6	57	100.0
>48 months	53	58.9	37	41.1	90	100.0
x^2 = 1.87, 1 df, NS						
Socioeconomic status						
High	47	57.3	35	42.7	82	100.0
Low	33	50.8	32	49.2	65	100.0
x^2 = 0.63, 1 df, NS						
Family size						
1 or 2 chn.	52	59.1	36	40.9	88	100.0
3 or more chn.	28	47.5	31	52.5	59	100.0
x^2 = 1.93, 1 df, NS						

Notwithstanding the finding that about half of the parents wanted guidance, only 20.6 per cent of them rated their child's behaviour as "not easy" or "very difficult" to manage (Table 22) - figure that comparable to Hewett, Newson and Newson's (1970) finding that 90 per cent of the parents in their sample rated their children as being happy most of the time, and Bayley's (1973) finding that 92.8 per cent of his sample of subnormal children living at home were rated as having no or slight behaviour problems. Although no separate analysis was carried out for the small number of Down's Syndrome children included in the present study, it is interesting to note that Carr (1975) found that parents of Down's Syndrome children tended to rate them as getting into more mischief than most children, compared with parents' ratings of a normal control group.

TABLE 27 : PARENTS' VIEWS ON EASE OF MANAGING THEIR CHILDRENS' BEHAVIOUR

Independent variable	Easy, unqualified		Easy, with reservations		Not easy/ V. difficult		Total	
	N	%	N	%	N	%	N	%
All families	71	48.6	45	30.8	30	20.6	146	100.0
Handicap								
Intellectual	30	53.6	13	23.2	13	23.2	56	100.0
Physical	28	56.0	16	32.0	6	12.0	50	100.0
Multi-	7	46.7	5	33.3	3	20.0	15	100.0
Other	6	24.0	11	44.0	8	32.0	25	100.0
X^2 = 10.05, 6 df, NS								
Residence								
Hamilton	18	47.4	13	34.2	7	18.4	38	100.0
Waikato	24	48.0	16	32.0	10	20.0	50	100.0
Auckland	29	50.0	16	27.6	13	22.4	58	100.0
X^2 = 0.59, 4 df, NS								
Age								
<48 months	30	54.6	18	32.7	7	12.8	55	100.0
>48 months	41	45.1	27	29.7	23	25.3	91	100.0
X^2 = 3.37, 2 df, NS								
Socioeconomic status								
High	42	51.9	23	28.4	16	19.7	81	100.0
Low	29	44.6	22	33.9	14	21.5	65	100.0
X^2 = 0.79, 2 df, NS								
Family size								
1 or 2 chn.	40	45.5	32	36.4	16	18.2	88	100.0
3 or more chn.	31	53.5	13	22.4	14	24.1	58	100.0
X^2 = 3.27, 2 df, NS								

Just over one-quarter (26.6 per cent) of the parents said that they had actually received some guidance in managing their children's behaviour - a proportion that was significantly higher for parents of children under the age of 48 months (Table 23). Of those who had received guidance, about two-thirds considered that there was a positive outcome, the remaining one-third feeling that the outcome was either unclear or negative. One parent articulated the problems of some of the parents who were less than satisfied with the guidance they received. In discussing her daughter's bedtime tantrums and her attempts to follow a psychologist's advice, she commented that "it was hard to enforce the instructions because of her strength, and the sheer endurance demanded of parents." Such comments raise the issue of the adequacy of professionals supervision of management programmes they advise parents to undertake.

Another quarter of the sample (24.7 per cent) indicated they had not received guidance in managing their children's behaviour, but would have liked some. However, not all of this group felt that they were not coping or were inadequate. Some expressed the need for guidance because they felt there was always something more they could learn, while some were anticipating the possibility of future problems when the child becomes more mobile, or starts to interact with more people.

TABLE 23 : PARENTS' VIEWS OF VALUE OF GUIDANCE IN MANAGING THEIR CHILDRENS' BEHAVIOUR

Independent variable	Received help: Positive outcome N	%	Received help: Unclear/ negative outcome[1] N	%	No help would have liked some N	%	No problem No need of help N	%	Total N	%
All families	26	17.3	14	9.3	37	24.7	73	48.7	150	100.0
Handicap										
Intellectual	10	17.2	6	10.4	16	27.6	26	44.8	58	100.0
Physical	8	15.7	3	5.9	8	15.7	32	62.8	51	100.0
Multi-	4	26.7	2	13.3	3	20.0	6	40.0	15	100.0
Other	4	15.4	3	11.6	10	38.5	9	34.6	26	100.0
x^2 = 9.54, 9 df, NS										
Residence										
Hamilton	4	10.3	4	10.3	13	33.3	18	46.2	39	100.0
Waikato	10	19.2	3	5.8	15	28.9	24	46.2	52	100.0
Auckland	12	20.3	7	11.9	9	15.3	31	52.5	59	100.0
x^2 = 6.67, 6 df, NS										
Age										
<48 months	4	6.9	6	10.3	12	20.7	36	62.1	58	100.0
>48 months	22	23.9	8	8.6	25	27.2	37	40.2	92	100.0
x^2 = 10.14, 3 df, p<.02										
Socioeconomic status										
High	19	22.6	8	9.6	19	22.6	38	45.2	84	100.0
Low	7	10.6	6	9.1	18	27.3	35	53.0	66	100.0
x^2 = 3.87, 3 df, NS										
Family size										
1 or 2 chn.	15	16.7	11	12.2	21	23.3	43	47.8	90	100.0
3 or more chn.	11	18.3	3	5.0	16	26.7	30	50.0	60	100.0
x^2 = 2.27, 3 df, NS										

[1] 6.0% unclear outcome, 3.3% negative outcome.

Parents' reports on what they considered to be the most effective means of controlling their children's behaviour gave the highest ranking to praise (48.0 per cent), with 20.6 per cent being unwilling to commit themselves because their strategies depended on the situation (Table 24). Physical punishment, either by itself or in association with explanations, was favoured by 11.0 per

cent - a somewhat lower proportion than might be expected from Hewett, Newson and Newson's (1970) finding that 33 per cent of the mothers of a sample of spastic children reported that they never or almost never smacked their handicapped children. When questioned about their approach to rewarding appropriate behaviours, social reinforcers alone were favoured in a ratio of two to one over strategies that included tangible reinforcers (Table 25).

TABLE 24 : PARENTS' VIEWS ON THE MOST EFFECTIVE MEANS OF BEHAVIOURAL CONTROL[1]

Type of control	N	%
Praise	35	48.0
Depends on situation	15	20.6
Physical punishment / explanation + smacking	8	11.0
Praise + rewards / rewards	6	8.2
Ignoring / time out / isolation	5	6.9
Explanations	3	4.1
Deprivation of privileges	1	1.4
Total	73	100.0

[1] 1979-80 data only.

TABLE 25 : PARENTS' VIEWS ON REWARDING APPROPRIATE BEHAVIOURS IN THEIR CHILDREN

Type of reward	N	%
Social reinforcers only	96	65.7
Tangible / Tangible + social	49	33.6
Never rewards	1	0.7
Total	146	100.0

5.4 Play Activities

One-third of the parents expressed a definite interest in knowing more about play activities for their children, compared with one-sixth who had a little interest in this area and half who had no interest (Table 26). The parents living in the Auckland area were significantly less interested in learning more about play than those living in Hamilton and Waikato. No comparable analysis could be found in the research literature.

TABLE 26 : PARENTS' WISHES TO KNOW MORE ABOUT PLAY ACTIVITIES FOR THEIR CHILDREN

Independent variable	Definite interest		Little or some interest		No interest		Total	
	N	%	N	%	N	%	N	%
All families	51	34.2	24	16.1	74	49.7	149	100.0
Handicap								
Intellectual	22	37.9	11	19.0	25	43.1	58	100.0
Physical	13	25.0	8	15.4	31	59.6	52	100.0
Multi-	4	26.7	2	13.3	9	60.0	15	100.0
Other	12	50.0	3	12.5	9	37.5	24	100.0
x^2 = 6.67, 6 df, NS								
Residence								
Hamilton	22	57.9	7	18.4	9	23.7	38	100.0
Waikato	22	43.1	7	13.7	22	43.1	51	100.0
Auckland	7	11.7	10	16.7	43	71.7	60	100.0
x^2 = 28.09, 4 df, p<.001								
Age								
<48 months	21	35.0	9	15.0	30	50.0	60	100.0
>48 months	30	33.7	15	16.9	44	49.4	89	100.0
x^2 = 0.10, 2 df, NS								
Socioeconomic status								
High	29	35.4	15	18.3	38	46.3	82	100.0
Low	22	32.8	9	13.4	36	53.7	67	100.0
x^2 = 1.02, 2 df, NS								
Family size								
1 or 2 chn.	32	36.0	11	12.4	46	51.7	89	100.0
3 or more chn.	19	31.7	13	21.7	28	46.7	60	100.0
x^2 = 2.30, 2 df, NS								

5.5 Parents' Reactions to Attending Parent Training Courses

The parents were asked how they would feel about attending training courses or groups that were run for parents of children like their own. Of the 151 mothers who responded to this question, 61.6 per cent were very positive, another 28.5 per cent were positive with reservations, and the remaining 9.9 per cent were unsure or negative (Table 27).

TABLE 27 : MOTHERS' REACTIONS TO ATTENDING PARENT TRAINING COURSES

Independent variable	Very positive		Positive with reservation		Unsure/ Negative[1]		Total	
	N	%	N	%	N	%	N	%
All families	93	61.6	43	28.5	15	9.9	151	100.0
Handicap								
Intellectual	36	62.1	15	25.9	7	12.1	58	100.0
Physical	32	61.5	14	26.9	6	11.6	52	100.0
Multi-	8	53.3	7	46.7	0	.0.0	15	100.0
Other	17	65.4	7	26.9	2	7.8	26	100.0
X^2 = 4.20, 6 df, NS								
Residence								
Hamilton	30	76.9	9	23.1	0	0.0	39	100.0
Waikato	31	59.6	16	30.8	5	9.7	52	100.0
Auckland	32	53.3	18	30.0	10	16.7	60	100.0
X^2 = 9.35, 4 df, NS								
Age								
<48 months	38	63.3	18	30.0	4	6.6	60	100.0
>48 months	55	60.4	25	27.5	11	12.1	91	100.0
X^2 = 1.20, 2 df, NS								
Socioeconomic status								
High	51	60.7	26	31.0	7	8.4	84	100.0
Low	42	62.7	17	25.4	8	12.0	67	100.0
X^2 = 0.92, 2 df, NS								
Family size								
1 or 2 chn.	60	66.7	24	26.7	6	6.6	90	100.0
3 or more chn.	33	54.1	19	31.2	9	14.8	61	100.0
X^2 = 3.50, 2 df, NS								

[1] 4.6% unsure and 5.3% negative

The distribution was markedly different for the 91 fathers, the comparable findings being 45.1, 37.4 and 17.6 per cent, respectively (Table 28), with fathers living in the Hamilton area being markedly more positive in their reactions to attending parent training courses than those in Auckland or the Waikato.

The only comparable study against which these results can be measured is that of Lonsdale (1978). She reported that only 54.6 per cent of her sample of parents considered parent support groups to be essential or important - a somewhat less positive attitude than was found in the present sample. A more direct indication of parents' willingness to participate in training programmes

can be found in early intervention studies. In one such study, Mitchell, Parker and Ward (1981) reported that of the 17 families of Down's Syndrome infants who were given the opportunity to participate in an individualised parent training programme, 15 accepted, although two subsequently transferred to another programme. Several families travelled more than 100 kilometres each way every two or three weeks to participate in the programme.

TABLE 28 : FATHERS' REACTIONS TO ATTENDING PARENT TRAINING COURSES

Independent variable	Very positive		Positive with reservation		Unsure/ Negative[1]		Total	
	N	%	N	%	N	%	N	%
All families	41	45.1	34	37.4	16	17.6	91	100.0
Handicap								
Intellectual	15	41.7	15	41.7	6	16.7	36	100.0
Physical	15	53.6	6	21.4	7	25.0	28	100.0
Multi-	4	36.4	7	63.6	0	0.0	11	100.0
Other	7	43.8	6	37.5	3	18.8	16	100.0
X^2 = 7.69, 6 df, NS								
Residence								
Hamilton	21	72.4	6	20.7	2	7.0	29	100.0
Waikato	11	36.7	12	40.0	7	23.3	30	100.0
Auckland	9	28.1	16	50.0	7	21.9	32	100.0
X^2 = 13.69, 4 df, p<.01								
Age								
<49 months	19	46.3	17	41.5	5	12.2	41	100.0
>48 months	22	44.0	17	34.0	11	22.0	50	100.0
X^2 = 1.60, 2 df, NS								
Socioeconomic status								
High	27	47.4	22	38.6	8	14.1	57	100.0
Low	14	41.2	12	35.3	8	23.5	34	100.0
X^2 = 1.34, 2 df, NS								
Family size								
1 or 2 chn.	29	52.7	17	30.9	9	16.4	55	100.0
3 or more chn.	12	33.3	17	47.2	7	19.4	36	100.0
X^2 = 3.48, 2 df, NS								

[1] 11.0% unsure and 6.6% negative

The main reservations about attending courses centred on two main themes. Firstly, several parents felt that they would not have sufficient time - one because of shift work, several because they lived in rural areas, some because they lacked transport, and one because of their commitment to the rest of the family (*We try to be balanced. 102).*

Secondly, some parents were skeptical about the value of courses, as can be seen from these comments:

> *The people running these courses often appear to lack enough first hand real experience of the specific handicap and problems to be really useful. (134).*
>
> *What are they going to teach me? I don't think I have a problem. All the pushing and prodding hasn't affected ___. He goes at his own pace. You can't speed him up. Help is marvellous, but he hasn't developed any faster! (139).*
>
> *Psychologists etc. don't seem to realise how hard it is to apply their suggestions. (079).*

Several parents said that they would only attend courses if they could be assured that they were relevant and specific to their child's needs, implying that their impressions of such courses were that they were too general.

Other reservations to be expressed by individual parents are reflected in the following:

> *I don't want to be anchored by her handicap any more. I want other people to do it. (124).*
>
> *When you are coping with sheer survival you don't need people to tell you what you can do all day. (154).*
>
> *I've never got involved with anything. I'm scared of getting involved with anything. (159).*

5.6 Familiarity with *Your Child Is Different*

When the second phase of the survey was carried out in 1979-1980, Radio New Zealand had broadcast the radio series 'Your Child is Different' and had distributed the accompanying booklet (Mitchell, 1979) of the same title free to any person who requested it. In order to test out the extent to which material of direct relevance to the survey sample had been disseminated and/or taken up by the parents, the second phase questionnaire included items on this material. From Table 29 it can be seen that half of the parents had read the booklet, a proportion that was consistent across the various independent variables.

TABLE 29 : PARENTS' READING OF BOOKLET, 'YOUR CHILD IS DIFFERENT'[1]

Independent variable	Read booklet		Did not read booklet		Total	
	N	%	N	%	N	%
All families	42	49.4	43	50.6	85	100.0
Handicap						
Intellectual	17	54.8	14	45.2	31	100.0
Physical	10	33.3	20	66.7	30	100.0
Multi-	8	80.0	2	20.0	10	100.0
Other	7	50.0	7	50.0	14	100.0
x^2 = 7.21, 3 df, NS						
Residence						
Hamilton	3	25.0	9	75.0	12	100.0
Waikato	7	53.9	6	46.2	13	100.0
Auckland	32	53.3	28	46.7	60	100.0
x^2 = 3.33, 2 df, NS						
Age						
<48 months	20	58.8	14	41.2	34	100.0
>48 months	22	43.1	29	56.9	51	100.0
x^2 = 2.00, 1 df, NS						
Socioeconomic status						
High	25	54.3	21	45.7	46	100.0
Low	17	43.6	22	56.4	39	100.0
x^2 = 0.98, 1 df, NS						
Family size						
1 or 2 chn.	27	50.9	26	49.1	53	100.0
3 or more chn.	15	46.9	17	53.1	32	100.0
x^2 = 0.13, 1 df, NS						

[1] 1979-80 data only.

A lower proportion of the sample had listened to the radio series, 'Your Child is Different' than had read the booklet (35.3 per cent, compared with 49.4 per cent). Significant differences were recorded in the proportion of parents who listened to the series, with a higher proportion of parents of multi-handicapped and of parents of smaller families reporting that they had done so (Table 30).

TABLE 30 : PARENTS' LISTENING TO RADIO SERIES, 'YOUR CHILD IS DIFFERENT'[1]

Independent variable	Listened to series		Did not listen to series		Total	
	N	%	N	%	N	%
All families	30	35.3	55	64.7	85	100.0
Handicap						
Intellectual	10	32.3	21	67.7	31	100.0
Physical	7	23.3	23	76.7	30	100.0
Multi-	8	80.0	2	20.0	10	100.0
Other	5	35.7	9	64.3	14	100.0
x^2 = 10.76, 3 df, p<.02						
Residence						
Hamilton	3	25.0	9	75.0	12	100.0
Waikato	6	46.2	7	53.9	13	100.0
Auckland	21	35.0	39	65.0	60	100.0
x^2 = 1.23, 2 df, NS						
Age						
<48 months	13	38.2	21	61.8	34	100.0
>48 months	17	33.3	34	66.7	51	100.0
x^2 = 0.21, 1 df, NS						
Socioeconomic status						
High	20	43.5	26	56.5	46	100.0
Low	10	25.6	29	74.4	39	100.0
x^2 = 2.94, 1 df, NS						
Family size						
1 or 2 chn.	23	43.4	30	56.6	53	100.0
3 or more chn.	7	21.9	25	78.1	32	100.0
x^2 = 4.05, 1 df, p<.05						

[1] 1979-80 data only.

5.7 Recommendations

Based on the above findings, it is recommended:

1. That parent training programmes should be made readily available to parents of handicapped children (Attwood, 1977; Bitter, 1963; Cunningham, 1975; Hornby, 1980; Jackson and Terdal, 1978; Mittler, 1979; Parker and Mitchell, 1980).

2. That such courses should

(a) be held in locations that minimise the amount of travel parents have to undertake;

(b) be directed at fathers as well as mothers;

(c) be concerned with meeting the needs of individual families, as well as covering general issues;

(d) recognise parents' rights to refuse to participate;

(e) be directed by professionals who are skilled at working with parents, as well as with handicapped children;

(f) have a home-based component to ensure adequate transfer of concepts;

(g) include consideration of such areas as language skills, behaviour management, feeding, toileting, dressing and play, in approximately that order.

CHAPTER SIX

PARENTS' FAMILIARITY AND SATISFACTION WITH SERVICES

If I'd known what to ask for - you don't know what's available. You find out months later you could or should have had something - a piece of equipment, home aid, or ideas about how to help your child learn to do something you thought he would find impossible because of his handicap - but by then it's often too late. You didn't know, and it's taken its toll on your health or your family or your marriage.

6.1 Overview

The parents were questioned regarding the extent to which they knew of and had used a range of professional services commonly associated with handicapping conditions. From Table 31, it can be seen that these contacts extended from just over half of the sample who had used the services of psychologists and visiting therapists (59.3 and 55.3 per cent, respectively), to one-fifth or fewer who had had contact with hospital social workers and district nurses (20.0 and 15.3 per cent, respectively).

TABLE 31 : EXTENT TO WHICH PARENTS KNOW OF AND HAVE USED VARIOUS PROFESSIONS : SUMMARY

Service	Did know of: Have used		Did know of: Have not used		Did not know of		Total	
	N	%	N	%	N	%	N	%
Psychologists	89	59.3	19	12.7	42	28.0	150	100.0
Visiting therapists	83	55.3	13	8.7	54	36.0	150	100.0
Speech therapists	69	46.0	13	8.7	68	45.3	150	100.0
Hearing assessment	68	45.3	17	11.3	65	43.3	150	100.0
Physiotherapists	63	42.0	25	16.7	62	41.3	150	100.0
Orthotists	40	26.7	36	24.0	74	49.3	150	100.0
Hospital social workers	30	20.0	23	15.3	97	64.7	150	100.0
District nurses	23	15.3	29	19.3	98	65.3	150	100.0

[1] Parents were not questioned about all of the professional groups with whom they came into contact; for example - the medical profession was not focused on in this question.

In terms of the proportion of respondents who rated the professionals as 'very helpful', visiting therapists, with 67.9 per cent in this category, stood out (Table 32). They were followed by speech therapists and medical specialists (excluding paediatricians), both of which had slightly more than 50 per cent of the respondents rating them as very helpful. Then followed a group of professions comprising Crippled Children Society field officers (44.0 per cent),

Society for the Intellectually Handicapped social workers (40.8 per cent) and paediatricians (37.3 per cent). The two groups achieving the lowest proportion of 'very helpful' ratings were psychologists (25.9 per cent) and hospital social workers (23.5 per cent).

TABLE 32 : PARENTS' RATINGS OF HELPFULNESS OF VARIOUS PROFESSIONAL GROUPS[1]

Professionals	Very helpful N	Very helpful %	Some help N	Some help %	Not sure[3] N	Not sure[3] %	Not helpful N	Not helpful %	Total N	Total %
Visiting therapists	57	67.9	18	21.4	5	6.0	4	4.8	84	100.0
Medical specialists[2,4]	24	54.5	11	25.0	3	6.8	6	13.6	44	100.0
Speech therapists	38	54.3	16	22.9	7	10.0	9	12.9	70	100.0
CCS Field Officers	37	44.0	29	34.5	3	3.6	15	17.9	84	100.0
Family doctors[2]	28	42.4	17	25.8	8	12.1	13	19.7	66	100.0
Plunket Nurses	15	41.7	6	16.7	5	13.9	10	27.8	36	100.0
SIH Social Workers	29	40.8	20	28.2	9	12.7	13	18.3	71	100.0
Paediatricians[2]	28	37.3	18	24.0	20	26.7	9	12.0	75	100.0
Psychologists	22	25.9	18	21.2	12	14.1	33	38.8	85	100.0
Hospital social workers	8	23.5	8	23.5	9	26.5	9	26.5	34	100.0

[1] Minor discrepancies occur between data in this and previous table because not all parents who said they used a service rated its helpfulness.

[2] 1979-80 data only.

[3] Includes : varied from professional to professional, not sure, neutral, only brief contacts.

[4] Excluding paediatricians.

These figures should be considered in conjunction with the data relating to the proportion of parents who rated the professionals as being 'not helpful'. In general, these ratings were the reciprocal of the 'very helpful' ratings, the major exceptions being paediatricians who were rated eighth in terms of the 'very helpful' category but second in the 'not helpful' category, and plunket nurses who were sixth in the former and ninth in the latter categories.

Although parents were not asked to give reasons for their ratings of the various professionals, it would seem that those achieving the highest rankings have practical advice and frequent contacts in common. The former of these points has already been noted as being valued by the parents in this sample (see Chapter Four), while Cunningham and Sloper (1977) have presented data in support

of the latter.

The subsequent sections of this chapter will discuss the results pertaining to each professional group in more detail.

6.2 Psychological Services

Psychological Services had been used by three out of every five families (Table 33), with one in eight knowing of such services but not having used them and just over one-quarter not knowing of their existence. This pattern was generally true irrespective of the child's handicap, place of residence and family size. There were significant trends, however, for older rather than younger children to have been seen by psychologists (X^2 = 26.01, 2df, p<,001) and for higher rather than lower socioeconomic status families to have had such contacts (X^2 = 5.32, 2df, p<.05). Of those children who had been seen by psychologists, just under half (47.1 per cent) had found the contacts helpful, one-quarter were unsure, and one-quarter rated them as being not helpful (Table 32).

The finding that 59.3 per cent of the sample had seen a psychologist is consistent with Hallinan's (1978) figure of 53.2 per cent, but considerably higher than in Kirkland's (1981) survey of the parents of 113 New Zealand deaf children in which only 30 per cent had been seen by a psychologist and in Chazan's (1979) U.K. sampling of 145 parents with handicapped children under the age of five years.[1]

Only 35.0 per cent of the families with children under the age of four years had had contact with a psychologist, a figure that was somewhat lower than the 44.2 per cent of Hallinan's (1978) sample whose initial contact with a psychologist was when their child was under four.

With just under half of the families finding their contacts with psychologists helpful, the parents in this study showed a similar pattern to Hallinan's (1978) parents, 53.9 per cent of whom rated psychologists as 'very helpful' or of 'some value'. Higher levels of satisfaction were expressed by a sample of

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[1] All three of these researchers reported that they may well have underestimated the number of families who had had contacts with psychologists since the parents are not always sure of the professions of all the people they had seen in connection with their child or because the parents may not have always been informed that their child had been seen. This point is recognised as a possible source of distortion in the data in the present study - not only with respect to psychologists.

parents in the Hamilton centre of the Education Department's Psychological Service (Hills and Turner, 1981). In this study, 71 per cent of the parents expressed themselves as satisfied with their contacts - although it must be noted that the sample was restricted to those who had had more than one-contact assessments.

TABLE 33 : EXTENT TO WHICH PARENTS KNOW OF AND HAVE USED PSYCHOLOGICAL SERVICES

Independent variable	Did know of: Have used		Did know of: Have not used		Did not know of		Total	
	N	%	N	%	N	%	N	%
All families	89	59.3	19	12.7	42	28.0	150	100.0
Handicap								
Intellectual	36	61.0	6	10.2	17	28.8	59	100.0
Physical	27	51.9	7	13.5	18	34.6	52	100.0
Multi-	9	60.0	3	20.0	3	20.0	15	100.0
Other	17	70.8	3	12.5	4	16.7	24	100.0
x^2 = 4.27, 6 df, NS								
Residence								
Hamilton	21	53.9	4	10.3	14	35.9	39	100.0
Waikato	33	64.7	3	5.9	15	29.4	51	100.0
Auckland	35	58.3	12	20.0	13	21.7	60	100.0
x^2 = 6.80, 4 df, NS								
Age								
<48 months	21	35.0	10	16.7	29	48.3	60	100.0
>48 months	68	75.6	9	10.0	13	14.4	90	100.0
x^2 = 26.01, 2 df, p<.001								
Socioeconomic status								
High	57	68.7	8	9.6	18	21.7	83	100.0
Low	32	47.8	11	16.4	24	35.8	67	100.0
x^2 = 6.72, 2 df, p<.05								
Family size								
1 or 2 chn.	50	55.6	16	17.8	24	26.7	90	100.0
3 or more chn.	39	65.0	3	5.0	18	30.0	60	100.0
x^2 = 5.32, 2 df, NS								

6.3 Medical Contacts in general

In the first phase of the study, parents were asked about their general level of satisfaction with medical contacts. Of the 67 respondents to this question, one-quarter expressed themselves as very satisfied, another quarter as fairly satisfied, one-third as unsure (on grounds that included variations among professionals), and the remaining one-sixth as not satisfied. Statistically

significant differences in the distribution in this variable were recorded for place of residence, with parents in Hamilton tending to be more equivocal or negative in their evaluations of medical services than those in the smaller towns and rural areas of Waikato. When the 11 respondents who were unable to form an opinion because of variations from professional to professional are excluded from the calculations, a total of 58.9 per cent of the parents in this phase were very or fairly satisfied with their medical contacts.

The level of satisfaction expressed by the parents about their contacts with the medical profession was comparable to Pulman's (1979(a)) finding that 64.0 per cent of the parents in her sample had found the medical services for their child since birth to be either satisfactory or very satisfactory (although only 27 per cent indicated that they were similarly satisfied with doctors' advice at the time of the child's birth). The present results are comparable, too, to Hewett, Newson and Newson's (1970) finding that 56 per cent of their sample had found their family doctors to be helpful and to Fox's (1974) and Bayley's (1973) finding that around two-thirds of the parents of handicapped children rated doctors positively or neutrally. These results all fall considerably short of Walker, Thomas and Russell's (1971) finding that of a sample of parents of spina bifida children, 76.7 per cent rated the assessments of their general practitioners as very or fairly helpful.

If this latter finding is excluded, it would seem that the medical profession has a 'satisfaction rating' of between half and two-thirds among parents of handicapped children, albeit a rating which extends from considerable to rather modest levels of satisfaction.

6.4 Visiting Therapists

From Table 34, it can be seen that Visiting Therapists (see Barnett (1980) for a description of their roles) had been used by 55.3 per cent of the families, with another 8.7 per cent knowing of the service but not using it and 36.0 per cent who did not know of it. This pattern differed significantly according to the child's handicap, families with physically or multi-handicapped children making greater use of the service than those with the other two categories of handicap. Although there was a tendency for Auckland parents to have used the service more than parents in the other two locations and for families with children over the age of four years to have used it more than those with children under four, these differences were statistically not significant.

TABLE 34 : EXTENT TO WHICH PARENTS KNOW OF AND HAVE USED VISITING THERAPY SERVICES

Independent variable	Have used		Did know of Have not used		Did not know of		Total	
	N	%	N	%	N	%	N	%
All families	83	55.3	13	8.7	54	36.0	150	100.0
Handicap								
Intellectual	20	33.9	7	11.9	32	54.2	59	100.0
Physical	41	78.8	3	5.8	8	15.4	52	100.0
Multi-	11	73.3	1	6.7	3	20.0	15	100.0
Other	11	45.8	2	8.3	11	45.8	24	100.0
X^2 = 25.94, 6 df, p<.001								
Residence								
Hamilton	16	41.0	4	10.3	19	48.7	39	100.0
Waikato	27	52.9	3	5.9	21	41.2	51	100.0
Auckland	40	66.7	6	10.0	14	23.3	60	100.0
X^2 = 8.39, 4 df, NS								
Age								
<48 months	40	66.7	3	5.0	17	28.3	60	100.0
>48 months	43	47.8	10	11.1	37	41.1	90	100.0
X^2 = 5.51, 2 df, NS								
Socioeconomic status								
High	44	53.0	8	9.6	31	37.3	83	100.0
Low	39	58.2	5	7.5	23	34.3	67	100.0
X^2 = 0.48, 2 df, NS								
Family size								
1 or 2 chn.	53	58.9	6	6.7	31	34.4	90	100.0
3 or more chn.	30	50.0	7	11.7	23	38.3	60	100.0
X^2 = 1.70, 2 df, NS								

As noted in Table 32, Visiting Therapists were rated very highly by those parents who had used their services, with 67.9 per cent finding them very helpful and 21.4 per cent of some help.

6.5 Physiotherapy Services

Physiotherapy services had been used by 42.0 per cent of the total sample, while another 16.7 per cent know of the existence of such services but had not availed themselves of them (Table 35). This pattern differed significantly according to handicap, with families of physically handicapped and multi-handicapped children availing themselves of physiotherapy services more than the other two categories. Auckland families and families with children under the age of 48 months had used

the services more than those from other centres or those with older handicapped children, respectively.

TABLE 35 : EXTENT TO WHICH PARENTS KNOW OF AND HAVE USED PHYSIOTHERAPY SERVICES

Independent variable	Did know of: Have used		Did know of: Have not used		Did not know of		Total	
	N	%	N	%	N	%	N	%
All families	63	42.0	25	16.7	62	41.3	150	100.0
Handicap								
Intellectual	14	23.7	11	18.6	34	57.6	59	100.0
Physical	34	65.4	7	13.5	11	21.2	52	100.0
Multi-	7	46.7	2	13.3	6	40.0	15	100.0
Other	8	33.3	5	20.8	11	45.8	24	100.0
x^2 = 21.81, 6 df, p<.01								
Residence								
Hamilton	12	30.8	8	20.5	19	48.7	39	100.0
Waikato	15	29.4	7	13.7	29	56.9	51	100.0
Auckland	36	60.0	10	16.7	14	23.3	60	100.0
x^2 = 16.53, 4 df, p<.01								
Age								
<48 months	35	58.3	8	13.3	17	28.3	60	100.0
>48 months	28	31.1	17	18.9	45	50.0	90	100.0
x^2 = 11.11, 2 df, p<.01								
Socioeconomic status								
High	38	45.8	13	15.7	32	38.6	83	100.0
Low	25	37.3	12	17.9	30	44.8	67	100.0
x^2 = 1.09, 2 df, NS								
Family size								
1 or 2 chn.	38	42.2	14	15.6	38	42.2	90	100.0
3 or more chn.	25	41.7	11	18.3	24	40.0	60	100.0
x^2 = 0.21, 2 df, NS								

6.6 Hearing Assessment Services

Just over half of the families knew of the existence of hearing assessment services with four out of five of those who know of them having used them at some stage (Table 36). There was no significant difference within the sample according to any of the independent variables.

TABLE 36 : EXTENT TO WHICH PARENTS KNOW OF AND HAVE USED HEARING ASSESSMENT SERVICES

Independent variable	Did know of: Have used		Did know of: Have not used		Did not know of		Total	
	N	%	N	%	N	%	N	%
All families	68	45.3	17	11.3	65	43.3	150	100.0
Handicap								
Intellectual	25	42.4	6	10.2	28	47.5	59	100.0
Physical	20	38.5	7	13.5	25	48.1	52	100.0
Multi-	8	53.3	1	6.7	6	40.0	15	100.0
Other	15	62.5	3	12.5	6	25.0	24	100.0
X^2 = 5.42, 6 df, NS								
Residence								
Hamilton	16	41.0	4	10.3	19	48.7	39	100.0
Waikato	20	39.2	3	5.9	28	54.9	51	100.0
Auckland	32	53.3	10	16.7	18	30.0	60	100.0
X^2 = 8.61, 4 df, NS								
Age								
<48 months	25	41.7	5	8.3	30	50.0	60	100.0
>48 months	43	47.8	12	13.3	35	38.9	90	100.0
X^2 = 2.12, 2 df, NS								
Socioeconomic status								
High	36	43.4	8	9.6	39	47.0	83	100.0
Low	32	47.8	9	13.4	26	38.9	67	100.0
X^2 = 1.20, 2 df, NS								
Family size								
1 or 2 chn.	45	50.0	10	11.1	35	38.9	90	100.0
3 or more chn.	23	38.3	7	11.7	30	50.0	60	100.0
X^2 = 2.12, 2 df, NS								

6.7 Speech Therapy Services

From Table 37, it can be seen that speech therapy services had been used by just under half of the families (46.0 per cent) with nearly one in ten (8.7 per cent) knowing of their existence but not using them. This pattern of use (or access) is similar to Kirkland's finding that 52 per cent of her sample of deaf children were receiving speech therapy. The pattern of use was broadly true with respect to each of the independent variables, except for age when there was a significant tendency for older children to have had assistance (X^2 = 9.04, 2 df, $p<.02$). Speech therapists received positive ratings from the parents, with 77.2 per cent of them finding them very helpful or of some help (Table 32).

TABLE 37 : EXTENT TO WHICH PARENTS KNOW OF AND HAVE USED SPEECH THERAPY SERVICES

Independent variable	Did know of: Have used N	Did know of: Have used %	Did know of: Have not used N	Did know of: Have not used %	Did not know of N	Did not know of %	Total N	Total %
All families	69	46.0	13	8.7	68	45.3	150	100.0
Handicap								
Intellectual	21	35.6	7	11.9	31	52.5	59	100.0
Physical	24	46.2	3	5.8	25	48.1	52	100.0
Multi-	9	60.0	1	6.7	5	33.3	15	100.0
Other	15	62.5	2	8.3	7	29.1	24	100.0
X^2 = 7.34, 6 df, NS								
Residence								
Hamilton	16	41.0	4	10.3	19	48.7	39	100.0
Waikato	19	37.3	5	9.8	27	52.9	51	100.0
Auckland	34	56.7	4	6.7	22	36.7	60	100.0
X^2 = 4.75, 4 df, NS								
Age								
<48 months	19	31.7	8	13.3	33	55.0	60	100.0
>48 months	50	55.6	5	5.6	35	38.9	90	100.0
X^2 = 9.04, 2 df, p<.02								
Socioeconomic status								
High	40	48.2	6	7.2	37	44.6	83	100.0
Low	29	43.3	7	10.4	31	46.3	67	100.0
X^2 = 0.66, 2 df, NS								
Family size								
1 or 2 chn.	43	47.8	8	8.9	39	43.3	90	100.0
3 or more chn.	26	43.3	5	8.3	29	48.3	60	100.0
X^2 = 0.37, 2 df, NS								

6.8 Hospital Social Worker Services

Only a very small proportion of the parents had used hospital social workers and, of those who did, less than half rated them as being very helpful or of some help (see Table 32). These low ratings are consistent with those reported in other studies (Bayley, 1973; Fox, 1974; Hewett, Newson and Newson, 1970; Wilkin, 1979). Fox (1974), for example, described social workers as "the profession nobody understands", pointing out that even among parents who were in client relationships, there was a strong sense of uncertainty about the aims and motives of the professional social worker. Bayley (1973) thought that social workers were often put into impossible situations of not being in a position to offer families the help they needed in the day-to-day care of the

disabled child. In their comments on services for the intellectually handicapped in the North Canterbury Hospital region, Somerville, Barnett and Malcolm (1976) have pointed out that social workers have varying amounts of training and hence offer services with varying amounts of expertise. They suggest, too, that social workers are often involved too late : "On many occasions when social work intervention finally occurs, the feelings of rejection towards the intellectually handicapped member and maladaptation to the situation is firmly established." (p.72).

While the proportion of the total sample in the present study who had had contact with social workers was very small (in itself, a possible cause for concern), and they were not closely questioned on the reasons for their evaluation, the above comments may help put the findings in context. Further research is clearly required in this area.

TABLE 39 : EXTENT TO WHICH PARENTS KNOW OF AND HAVE USED DISTRICT NURSING SCHEME

Independent variable	Did know of Have used		Have not used		Did not know of		Total	
	N	%	N	%	N	%	N	%
All families	23	15.3	29	19.3	98	65.3	150	100.0
Handicap								
Intellectual	8	13.6	13	22.0	38	64.4	59	100.0
Physical	9	17.3	9	17.3	34	65.4	52	100.0
Multi-	2	13.3	4	26.7	9	60.0	15	100.0
Other	4	16.7	3	12.5	17	70.8	24	100.0
x^2 = 1.83, 6 df, NS								
Residence								
Hamilton	7	18.0	6	15.4	26	66.7	39	100.0
Waikato	9	17.7	10	19.6	32	62.8	51	100.0
Auckland	7	11.7	13	21.7	40	66.7	60	100.0
x^2 = 1.44, 4 df, NS								
Age								
<48 months	11	18.3	12	20.0	37	61.7	60	100.0
>48 months	12	13.3	17	18.9	61	67.8	90	100.0
x^2 = 0.82, 2 df, NS								
Socioeconomic status								
High	12	14.5	18	21.7	53	63.9	83	100.0
Low	11	16.4	11	16.4	45	67.2	67	100.0
x^2 = 0.69, 2 df, NS								
Family size								
1 or 2 chn.	11	12.2	17	18.9	62	68.9	90	100.0
3 or more chn.	12	20.0	12	20.0	36	60.0	60	100.0
x^2 = 1.88, 2 df, NS								

6.9 District Nursing Scheme

Table 38 shows the pattern of use of the District Nursing Scheme. The overall pattern of 15.3 per cent of the families having used the service, 19.3 per cent knowing of its existence but not having used it and 65.3 per cent not knowing about it did not vary significantly across the various independent variables.

6.10 Orthotic Services

From Table 39 it can be seen that orthotic services had been used by approximately one-quarter of the families, while another one-quarter knew about them but had not used them. Half of the sample did not know of them. As might be expected, this pattern varied significantly according to the child's handicap,

TABLE 39 : EXTENT TO WHICH PARENTS KNOW OF AND HAVE USED ORTHOTIC SERVICES

Independent variable	Did know of: Have used		Did know of: Have not used		Did not know of		Total	
	N	%	N	%	N	%	N	%
All families	40	26.7	36	24.0	74	49.3	150	100.0
Handicap								
Intellectual	5	8.5	17	28.8	37	62.7	59	100.0
Physical	25	48.1	9	17.3	18	34.6	52	100.0
Multi-	7	46.7	5	33.3	3	20.0	15	100.0
Other	3	12.5	5	20.8	16	66.7	24	100.0
X^2 = 31.00, 6 df, p<.001								
Residence								
Hamilton	13	33.3	4	10.3	22	56.4	39	100.0
Waikato	12	23.5	7	13.7	32	62.8	51	100.0
Auckland	15	25.0	25	41.7	20	33.3	60	100.0
X^2 = 19.39, 4 df, p<.001								
Age								
<48 months	15	25.0	16	26.7	29	48.3	60	100.0
>48 months	25	27.8	20	22.2	45	50.0	90	100.0
X^2 = 0.42, 2 df, NS								
Socioeconomic status								
High	28	33.7	23	27.7	32	38.6	83	100.0
Low	12	17.9	13	19.4	42	62.7	67	100.0
X^2 = 8.92, 2 df, p<.02								
Family size								
1 or 2 chn.	25	27.8	21	23.3	44	48.9	90	100.0
3 or more chn.	15	25.0	15	25.0	30	50.0	60	100.0
X^2 = 0.15, 2 df, NS								

with nearly half of the parents of physically and multiply handicapped children reporting they had used orthotic services. Significant variations occurred for place of residence, with families in Auckland tending to be more aware of the availability of orthotic services - even if they had not used them - than those living in the other two locations. Families of high socioeconomic status were both more familiar with and more likely to have used the services than those of low socioeconomic status.

6.11 Other Services

Data on the parents' knowledge and use of a range of services to which they might normally expect to have access are summarised in Table 40. Separate analyses were carried out according to the independent variables referred to in other sections of this report and these will be described where appropriate.

TABLE 40 : EXTENT TO WHICH PARENTS KNOW OF AND HAVE USED VARIOUS SERVICES

	Did know of				Did not know of		Total	
	Have used		Have not used					
Service	N	%	N	%	N	%	N	%
Home relief scheme	45	30.0	53	35.3	52	34.7	150	100.0
Home aid services/housework	14	9.3	36	24.0	100	66.7	150	100.0
" " " babysitting[1]	4	4.4	14	15.6	72	80.0	90	100.0
Napkin services	16	10.7	34	22.7	100	66.7	150	100.0
Social welfare benefits	87	58.0	22	14.7	41	27.3	150	100.0
Toy Libraries	67	44.7	47	31.3	36	24.0	150	100.0
Extramural Hospital wheelchairs	34	22.7	30	20.0	86	57.3	150	100.0

[1] Hamilton and Waikato parents only

A home relief scheme,[1] in which parents can be relieved of the responsibility for caring for their severely disabled child for up to four weeks each year, had been used by around one-third of the respondents; another one-third knew of their entitlements but had not taken advantage of them, while the remaining one-third did not know of the scheme. A significantly different pattern was

[1] Otherwise known as Aid to Families Caring for a Disabled Child, a provision of the Disabled Persons Community Welfare Act (1975), administered by the Department of Social Welfare.

recorded across handicaps, with parents of intellectually and multi-handicapped children being more aware of and having used the scheme more than parents of the children in the other two categories. Age of child also made a difference, parents of older children being more likely to have availed themselves of the scheme than had parents of the younger children (37.8 per cent vs 18.3 per cent).

Home aid with housework or babysitting had been used by only a small proportion of the parents (9.3 per cent and 4.4 per cent, respectively. When asked about what services they felt should be provided, many parents focussed on their wish for ready access to practical relief in areas such as babysitting, some clearly being unaware of what access they had to such assistance:

> *There should be a hostel during the Christmas period available for short stages, especially for a couple of hours. (083).*
>
> *There should be a local babysitting service - small short breaks. (099).*
>
> *We need babysitters for normal children when the handicapped child has to visit hospital. (105).*
>
> *An occasional person to mind them one day a week. (131).*

Napkin services in which parents can arrange for napkins to be laundered were known to one-third of the parents, but had been used by only one-third of that group. This pattern showed a geographic difference, with parents in Hamilton and Waikato being generally more familiar with the service.

Benefits such as the Handicapped Childs' Allowance (instituted October 1978), the Disability Allowance (instituted October 1975) and loans for alterations to homes were known to nearly three-quarters of the sample (72.7 per cent). Parents of intellectually and multi-handicapped children were more familiar with and had taken more advantage of such benefits than parents of the other two categories of handicap. Families in Auckland were much more aware of their entitlements than those in Hamilton and Waikato, with 81.7 per cent, 43.6 per cent and 41.6 per cent, respectively, having availed themselves of a benefit of one kind or another. This latter finding, however, may have been distorted by the fact that most of the Hamilton and Waikato families were surveyed in 1978, prior to the implementation of the Handicapped Child's Allowance. For a survey of the historical development and current use of such benefits, see a paper by Baird, (1981). Notwithstanding the above findings, several parents commented that they were unaware of or unable to obtain ready access to information regarding their entitlements to benefits:

> *We need some avenue to present to parents, as of right, all services, benefits, etc. that are available and who to contact. (078).*

I don't know enough about what I can get. (111).

We need a social welfare booklet on what benefits are available. (117).

Everything is there! The biggest problem is being put in touch with it and being aware that it is there. (129).

Once we found out what was available we were staggered. We got so much help, but could have had some from the start. (137).

Toy libraries had been used by 44.7 per cent of the families, while another 31.3 per cent knew of them but had not used them. This pattern varied according to the child's handicap, with families of physically and multi-handicapped children having used them more than the families of the other two categories. Place of residence, too, influenced the pattern of use of toy libraries. Although a higher proportion of the Auckland families knew of the existence of such libraries (88.3 per cent) than those in Hamilton and Waikato (66.7 and 68.7 per cent, respectively), comparatively few of the Auckland families actually used them (35.0 per cent).

Extramural hospital wheelchair services had been used by 22.7 per cent of the families, while another 20.0 per cent knew of their existence. Not surprisingly, this pattern differed according to category of handicap, with physically handicapped and multi-handicapped (30.8 per cent and 46.7 per cent, respectively) having the highest level of use. Place of residence also had an effect, Auckland families (36.7 per cent) having used the services more frequently than those in Hamilton (10.3 per cent) and Waikato (13.7 per cent).

6.12 Recommendations

On the basis of the data outlined in this chapter, the following general recommendations are put forward:

1. That psychologists should increase the level of their involvement with the families of young children with special needs, especially in the light of the emerging thrust towards early intervention programmes for such children (Chazan, 1979; Mitchell, Parker and Ward, 1981; Warnock, 1978).

2. That hospital social workers and psychologists should closely examine the quality of their services to families of children with special needs in order to ascertain reasons for the relatively low levels of satisfaction with these professions expressed by parents.

3. That various professional groups working with families of young children with special needs should closely examine the model of service delivery provided by visiting therapists and speech therapists, in the light of the high levels of satisfaction with these services expressed by parents.

4. That local communities should develop ways of providing parents of young children with special needs with short-term relief in such areas as babysitting or in such practical tasks as housekeeping, where this assistance is not already readily available.

5. That the Social Welfare Department, in association with other statutory and voluntary agencies, provide parents and relevant professionals with regularly up-dated lists of the mandatory and discretionary benefits available to families of disabled children (Grant, 1981; Hallinan, 1978).

CHAPTER SEVEN

PARENTS' PREFERENCES FOR SCHOOL SETTINGS

We want him to imitate children better than himself, but we don't want him ill-treated by normal kids. (111)

The justification for and the effects of integrating, or 'mainstreaming' disabled children into regular school environments has emerged as one of the dominant issues in special education during the past decade (Mitchell, 1981(a), 1981(b)).

In the course of the present survey, the parents were asked what preferences they had for their child's educational setting. From Table 41, it can be seen that the majority of parents favoured settings in which there were maximum opportunities for their children to mix with non-handicapped children, either in a special class or in a unit attached to a regular school (61.3 per cent) or in a regular class within a regular school with access to some specialist help (14.0 per cent). Only one in six of the parents (14.7 per cent) favoured a segregated special school placement, while one in ten were uncertain.

This general pattern varied according to the type of handicap, with parents of intellectually and multi-handicapped children favouring special school placement (20.3 per cent at 33.3 per cent, respectively), compared with only 5.9 per cent and 8.0 per cent of the parents of physically and 'other' handicapped children.

Place of residence also made a difference to the pattern of choices, Auckland parents being more emphatic in their wish to have their child placed in some form of integrated school setting (83.0 per cent) compared with the Hamilton parents (74.4 per cent) and the Waikato parents (67.3 per cent).

Age of child revealed differences in the parents' choice of school setting, with 87.9 per cent of the parents of the under-four group wanting their children to be placed in integrated settings when they reached school age, compared with 67.4 per cent of the parents of the over-four group. Whether these results reflect the two groups' differential experience of school settings or a real shift in the attitudes of parents of disabled children towards the issue of integration is a question that is beyond the scope of the present study.

Overall, these results provide some empirical support for the policy of the New Zealand Society for the Intellectually Handicapped (1979) to the effect that:

As far as possible, the intellectually handicapped child should be included in normal school provisions, so that each child can attend the local school along with their non-handicapped peers. (p.19).

TABLE 41 : PARENTS' PREFERENCES FOR SCHOOL SETTINGS FOR THEIR CHILDREN

Independent variable	Special school		Integrated school		Normal School/other		Uncertain		Total	
	N	%	N	%	N	%	N	%	N	%
All families	22	14.7	92	61.3	21	14.0	15	10.0	150	100.0
Handicap										
Intellectual	12	20.3	36	61.0	4	6.8	7	11.9	59	100.0
Physical	3	5.9	35	68.6	11	21.6	2	3.9	51	100.0
Multi-	5	33.3	8	53.3	1	6.7	1	6.7	15	100.0
Other	2	8.0	13	52.0	5	20.0	5	20.0	25	100.0
x^2 = 19.51, 9 df, p<.05										
Residence										
Hamilton	5	12.8	26	66.7	3	7.7	5	12.8	39	100.0
Waikato	10	19.2	32	61.5	3	5.8	7	13.5	52	100.0
Auckland	7	11.9	34	57.6	15	25.4	3	5.1	59	100.0
x^2 = 12.94, 6 df, p<.05										
Age										
<48 months	4	6.9	41	70.7	10	17.2	3	5.2	58	100.0
>48 months	18	19.6	51	55.4	11	12.0	12	13.0	92	100.0
x^2 = 8.16, 3 df, p<.05										
Socioeconomic status										
High	13	15.9	51	62.2	9	11.0	9	11.0	82	100.0
Low	9	13.2	41	60.3	12	17.6	6	8.8	68	100.0
x^2 = 1.55, 3 df, NS										
Family size										
1 or 2 chn.	12	13.5	56	62.9	14	15.7	7	7.9	89	100.0
3 or more chn.	10	16.4	36	59.0	7	11.5	8	13.1	61	100.0
x^2 = 1.76, 3 df, NS										

Recommendation

On the basis of the present study and on one reported elsewhere (Mitchell, 1981(b)) it is recommended:

> That educational policy-makers take due account of the high degree of support that parents of young children with special needs have for the notion of their children being educated in regular school settings.

CHAPTER EIGHT

SUMMARY AND CONCLUSIONS

This chapter provides a brief summary of the principal results of the survey, as well as outlining the limitations of the study and bringing together some of the common threads that appear in the findings. The recommendations based upon the quantitative and qualitative data of this and other relevant studies are summarised.

8.1 Summary of Major Findings

The principal findings of the study are arranged under the chapter headings used in the report and are presented without comment.

Telling parents they have a handicapped child. Just over half of the sample had been *told* within the first week and 85 per cent had been informed by the time the child was two years of age (Table 9). Parents of I.H. children were more likely to have been told earlier than parents of other categories of handicap (Table 10).

Medical specialists such as obstetricians and paediatricians are the principal *professions involved in informing parents*, with 69 per cent of the sample reporting they had been first told by such professionals (Table 11).

Both parents had been *told together* in just under half of the cases (Table 12), but of the parents who had been told alone, the bulk (62.9 per cent) would have preferred being told together (Table 13).

Parents' needs for support. The major unmet need experienced by the parents was for *information*, nearly three in five indicating this (Table 14). Over two-thirds of the families felt no need for *counselling for reactions and feelings* and, correspondingly, only one in five felt they had insufficient support (Table 16). Nearly two-thirds of the parents had *met other parents of children* with special needs and, of the remainder, most would like to (Table 17).

Parents' views on their guidance needs. One in four of the parents wished to know more about helping their children learn *self care skills* in two or more of the areas of toileting, feeding, dressing and washing (Table 18). Of the parents who had been given guidance in these areas, three in four had found it helpful (Table 19). Help with feeding and toileting was wanted by four in ten families (Tables 20 and 21), while just over one in three wanted assistance in helping

their children learn dressing skills (Table 22), particularly those in the higher socioeconomic status group. Nearly two-thirds of the parents wanted to know more about helping their children's *language development*, this proportion being significantly lower in the Auckland area (Table 20). Parents' knowledge of ways of helping their children's language development was not significantly related to their children's stage of language development.

While just over half of the parents wanted more guidance in *managing their children's behaviour* (Table 21), only one-fifth thought that their children's behaviour was 'not easy' or was 'difficult' to manage (Table 22). Of those who had received help in this area, two-thirds felt that there were positive outcomes to the guidance (Table 23).

One-third of the parents expressed a definite interest in knowing more about *play activities* for their children. Significant differences on this variable were recorded on the basis of residence, with Auckland parents being notably uninterested (Table 26).

Very positive attitudes towards *parent training courses* were recorded, with only one in ten of the mothers and one in six of the fathers surveyed being unsure or negative towards the idea of attending such courses (Tables 27 and 28). Half of the sample surveyed in 1979-80 had read the booklet, *Your Child is Different* and just over one-third had listened to the companion radio programme. (Tables 29 and 30).

Parents' familiarity and satisfaction with services. Ratings of the various professional groups in terms of the proportion of parents who found their services 'very helpful' ranged from 67.9 per cent for visiting therapists to around 25 per cent for psychologists and social workers (Table 32).

Psychological services had been used by around 60 per cent of the families, with a significant tendency for children over the age of four and for high socio-economic families to have been seen by psychologists (Table 33).

Visiting therapy services had been used by just over half of the families, with significantly higher proportions of those with physically or multiply handicapped children receiving such services than in the other categories (Table 34).

Physiotherapy services had been used by four in ten of the families, with variations in usage according to handicap similar to those reported for visiting therapists. There was a significant tendency for parents of younger children to have used physiotherapy services more than parents of older children (Table 35).

Just under half of the sample had used *hearing assessment* and *speech therapy services* (Tables 36 and 37). In the latter case, there was a statistically significant difference between younger and older children, a higher proportion of the latter receiving such services.

The *district nursing* scheme had been used by around 15 per cent of the families, while around 65 per cent did not know about such services (Table 38).

Orthotic services had been used by approximately one-quarter of the families, but there were significant variations according to handicap (more used by families of physically and multiply handicapped children), residence (Hamilton and Waikato parents were less aware of such services than those in Auckland) and socioeconomic status (lower status families were less aware of the services than higher status families) (Table 39).

The *home relief scheme* had been used by three in ten of the families (Table 40), with a tendency for parents of intellectually handicapped and multiply handicapped to avail themselves of the scheme more than the parents of the other categories of handicap. Parents of older children had used the scheme more than parents of younger children.

Ten per cent or fewer of the families had used *napkin services* or home aid services to help with *housework* or *babysitting* (Table 40). The vast bulk of the families were unaware of their entitlements in these areas.

Social welfare benefits were known and used by six in ten of the families, (Table 40) the proportion being higher for parents of intellectually and multi-handicapped children. Significant differences in the use of benefits were noted according to place of residence, with the rate of usage among Auckland parents being almost twice as high as in Hamilton and Waikato.

Toy libraries had been used by 45 per cent of the families (Table 40), although those with intellectually handicapped children and those from Auckland were significantly lower.

Extramural hospital wheelchair services had been used by just over one in five of the families (Table 40), with Auckland families availing themselves of this service more than those in the other two areas. The usage rates were significantly higher for physically and multiply handicapped children.

Parents' preferences for school settings. Parents' opinions on what school settings they wanted for their children showed a clear preference for integration, with three-quarters of the sample favouring full integration or placement in a special unit integrated into a regular school (Table 41). This was particularly the case among parents of physically handicapped children, younger children and those living in Auckland.

8.2 Limitations of the Study

Although the findings of this study are generally in accord with those reported in the literature, four factors indicate that a cautious approach should be taken in extrapolating them to particular families of handicapped children. Firstly, although many of the variables yielded a fair measure of consensus, the variations in the pattern of results make it imperative that each family be viewed as a social entity with unique needs and perceptions. Secondly, it must be realised that the sample was skewed towards the higher socioeconomic levels and that there was an element of self-selection in obtaining the subjects for the study. Thirdly, although the 152 families surveyed provide a good data base for many of the variables, it must be remembered that in their appraisal of professional groups or particular services, the parents were commenting in some cases on quite small numbers of professionals or services and that these may not be representative of those in other parts of the country. The variations recorded on some of the variables according to place of residence emphasises the need to consider this point. Finally, the limitations of obtaining data from interviews, in particular the heavy reliance placed on self reports and on the recall of events which may span several years, must be recognised as potential sources of distortion.

Notwithstanding these limitations, it is argued that the study provides an adequate data base on which service delivery decisions could be based with some confidence for the geographic areas surveyed and is strongly suggestive of decisions that could be made elsewhere in New Zealand.

8.3 Summary and Recommendations

The recommendations presented in this report are grouped under four main headings.

8.3.1 Informing parents

1. Given the concerns expressed by many parents regarding the way in which professionals informed them about their child's handicap, it is recommended:

   (a) That the training programmes of the various professions likely to be involved in informing parents of the presence of handicapping conditions in their children include significant components of relevance to this aspect of their work. In particular, there should be reference to recent advances in the medical, educational and community provisions for handicapped children and to the need for sensitivity in interactions with the parents of handicapped children.

   (b) That since the medical profession bears the main responsibility for informing parents of their child's handicap, the above recommendation be accepted as a high priority by those responsible for designing medical education courses at both the under- and post-graduate levels, and that individual professionals accept their personal responsibility for becoming better informed and more skilled in this area (Chapter Three).

2. That professionals who are confronted with the responsibility of informing, or confirming to, parents that their child has a handicapping condition recognise that the majority of parents would prefer to be told with their spouse. They should recognise, however, that since a significant minority of parents would prefer to be told alone, the dynamics of each individual family should be considered when deciding how their responsibility is discharged - if, indeed, it is possible to exercise any control over it (Chapter Three).

3. That professionals working with parents of handicapped children immediately following their being informed of their child's condition should take account of the emotional impact of such information on the whole family and

   (a) arrange for parents to return for several interviews in order to clarify their understanding and to come to terms with their feelings;

   (b) help the parents to make contact with parents of children with similar handicaps, and

(c) ensure that some single person has responsibility for coordinating contacts with professionals and others (Chapter Four).

8.3.2 Parent training

1. That parent training programmes should be made readily available to parents of handicapped children (Chapter Five).

2. That such courses should

   (a) be held in locations that minimise the amount of travel parents have to undertake;

   (b) be directed at fathers as well as mothers;

   (c) be concerned with meeting the needs of individual families, as well as covering general issues;

   (d) recognise parents' rights to refuse to participate;

   (e) be directed by professionals who are skilled at working with parents, as well as with handicapped children;

   (f) have a home-based component to ensure adequate transfer of concepts;

   (g) include consideration of such areas as language skills, behaviour management, feeding, toileting, dressing and play, in approximately that order (Chapter Five).

8.3.3 Information dissemination

1. That all professionals who have contact with handicapped children be provided with regular updated reading lists relating to various handicaps (Chapter Four).

2. That directories of services relating to the needs of families of young children with handicaps be compiled for every region within New Zealand (Chapter Four).

4. That regional resource centres be established to provide an information service to professionals and parents concerned with young handicapped children (Chapter Four).

5. That the Social Welfare Department, in association with other statutory and voluntary agencies, provide parents and relevant professionals with regularly up-dated lists of the mandatory and discretionary benefits available to families of disabled children (Chapter Six).

8.3.4 Quality of services

1. That psychologists should increase the level of their involvement with the families of young children with special needs, especially in the light of the emerging thrust towards early intervention programmes for such children (Chapter Six).

2. That hospital social workers and psychologists should closely examine the quality of their services to families of children with special needs in order to ascertain reasons for the relatively low levels of satisfaction with these professions expressed by parents (Chapter Six).

3. That various professional groups working with families of young children with special needs should closely examine the model of service delivery provided by visiting therapists and speech therapists, in the light of the high levels of satisfaction with these services expressed by parents (Chapter Six).

8.3.5 School settings

1. That educational policy-makers take due account of the high degree of support that parents of young children with special needs have for the notion of their children being educated in regular school settings (Chapter Seven).

8.4 Conclusions

If we were to draw up a composite statement from the 150 parents in this study, it might read something like this:

> "As the parents of a handicapped child we want all those various professionals who deal with us to treat us with openness, honesty and sensitivity. While the presence of a handicapped child in our family is never easy to come to terms with, please recognise that we have good support from our family and friends and that we are not emotionally incapacitated by our problems. Some of us, however, do need counselling,

especially when we first find out about our child. Meeting other parents helps us to adjust, so please put us in touch with each other.

Above all, perhaps, what we want is information - up-to-date information on how we can help our child, information on the services that are available to us, and information on the benefits to which we are entitled.

The professionals we find most helpful are those who see us often and offer us practical advice. Although we may find some problems in attending parent training courses, don't underestimate our willingness to take part - especially if they are based in our local community and provide us with ideas relevant to our child.

When it comes to school, please remember that we would like our child to attend a regular school - provided special help is available.

Finally, we are the articulate parents. Not all of us are able or willing to share our concerns with others. Some of us feel that we have a long-term problem that other people don't really understand."

REFERENCES

Abramson, P.R., Gravink, M.J., Abramson, L.M. and Sommers, D. Early diagnosis and intervention of retardation: a survey of parental reactions concerning the quality of services rendered. Mental Retardation, 1977, 15, 28.

Annison, J.E. and Young, W.H.L. The future forms of residential services for mentally retarded people in Australia - A Delphi study. Australian Journal of Developmental Disabilities, 1980, 6, 167-180.

Attwood, T. The Priory Parents Workshop. Child: care, health and development, 1977, 3, 81-91.

Baird, J. Department of Social Welfare provisions for children with special needs due to physical or mental disability. Paper presented at Conference on The Child with Special Needs. Otago Postgraduate Medical Society, Dunedin, 1981.

Barnett, N. The New Zealand Visiting Therapy Service. In D.R. Mitchell (ed.). Papers from First National Conference on Exceptional Children, Vol.1, Hamilton, 1980.

Bayley, M. Mental Handicap and Community Care. London: Routledge and Kegan Paul, 1973.

Berg, J.M., Gilderdale, S. and Way, U. On telling parents of a diagnosis of mongolism. British Journal of Psychiatry, 1969, 115, 1195-1196.

Birenbaum, A. The mentally retarded child in the home and family cycle. Journal of Health and Social Behaviour, 1971, 12, 55-65.

Bitter, J.A. Attitude change by parents of trainable mentally retarded children as a result of group discussion. Exceptional Children, 1963, 30, 173-177.

Braine, M.S. Factors associated with impairment of the early development of prematures. Monographs of the Society for Research on Child Development, 1966, 31.

Bruininks, R.H., Thurlow, M.L., Thurman, S.K. and Fiorelli, J.S. Deinstitutionalisation and community services. Mental Retardation and Developmental Disabilities, 1980, 11, 55-101.

Carr, J. Mongolism: telling the parents. Developmental Medicine and Child Neurology, 1970, 12, 213-221.

Carr, J. Young Children with Down's Syndrome. London: Butterworths, 1975.

Chazan, J. Identification, assessment and treatment: the role of the educational psychologist. In A.F. Laing (ed.). Young Children with Special Needs. Swansea: Department of Education, University College of Swansea, 1979.

Court, S.D.M. (Chairman) Fit for the Future. Report of the Committee on Child Health Services. London: H.M.S.O., 1976.

Cunningham, C.C. Parents as therapists and educators. In C.C. Kiernan and P. Woodford (eds.). Behaviour Modification in the Severely Retarded. London: Butterworths, 1975.

Cunningham, C.C. Parent counselling. In M. Craft (ed.). Tredgold's Mental Retardation, 12th edition. London: Balliere - Tindale, 1979.

Cunningham, C.C. and Sloper, T. Parents of Down's Syndrome babies: their early needs. Child: Care Health and Development, 1977, 3, 325-347.

Dean, D. Closer look: a parent information service. Exceptional Children, 1975, 41, 527-530.

Drillien, C.M. and Wilkinson, E.M. Mongolism: when should parents be told. British Medical Journal, 1964, 2, 1306.

Elley, W.B. and Irving, J.C. Revised socioeconomic index for New Zealand. New Zealand Journal of Educational Studies, 1976, 11, 25-36.

Fergusson, D.M. and Horwood, L.J. The measurement of socioeconomic status for 1109 New Zealand families. New Zealand Journal of Educational Studies, 1979, 14, 58-66.

Fox, A.M. Families with handicapped children - a challenge to the caring professions. In They Get This Training but they Don't know how You Feel. West Sussex Action Research for Crippled Children, 1975.

Freeston, B.M. An enquiry into the effect of a spina bifida child upon family life. Developmental Medicine and Child Neurology, 1971, 13, 456-461.

Gath, A. Down's Syndrome and the Family: The Early Years. London: Academic Press, 1978.

Gayton, W.F. Management problems of mentally retarded children and their families. Pediatric Clinics of North America, 1975, 22, 561-570.

Gayton, W.F. and Walker, L. Down's Syndrome: informing the parents. American Journal of Disorders of Childhood, 1974, 127, 510-512.

Gilmore, D.W. and Oates, R.K. Counselling about Down's Syndrome: the parents' viewpoint. The Medical Journal of Australia, 1977, 2, 600-603.

Goddard, J. and Raynor, H. A community resource for handicapped children: Honeylands Family Support Unit. APEX, 1978, 5, 18-20.

Grant, J. Accommodation and Service Needs of Disabled Persons in Auckland: Community Development Department, Auckland Regional Authority, 1981.

Hallinan, P. The views of some parents of young handicapped children on the Psychological Service of the Department of Education. Journal of the New Zealand Psychological Service Association, 1978, 3, 27-32.

Hallinan, P. Thursday's child has far to go: counselling parents of handicapped children. In B. O'Rourke and J. Clough (eds.), Early Childhood in New Zealand. Auckland: Heinemann, 1978.

Hewett, S. and Newson, J. and Newson, E. The Family and the Handicapped Child - A Study of Cerebral Palsied Children in Their Homes. London: George Allen and Unwin, 1970.

Hills, M. and Turner, C. Children, parents and educational psychologists. Paper presented at the New Zealand Psychological Society Annual Conference, Wellington, 1981.

Hornby, G. Group counselling with parents of the intellectually handicapped. Mental Handicap in New Zealand, 1980, 5, 3-14.

Jackson, R.H. and Terdal, L. Parent education within a pediatric practice. Journal of Pediatric Psychology, 1978, 3, 2-5.

Jacobs, J. Perplexity, confusion and suspicion: a study of selected forms of doctor-patient interactions. Social Science and Medicine, 1971, 5, 151-157.

Kirkland, C. One Hundred Deaf Children. Wellington: New Zealand Federation for Deaf Children, 1981.

Kuek, S. and Laugesen, M. Diagnosis and referral in a Wellington sample of cerebral palsy children. Wellington: Management Services and Research Unit, Department of Health, Working Paper No. 88, 1979.

Laing, A.F. and Jones, G. Discovery of handicap. In A.F. Laing (ed.). Young Children with Special Needs. Swansea: Department of Education, University College of Swansea, 1979.

Lipton, H.L. and Svarstad, B. Sources of variation in clinicians' communication to parents about mental retardation. American Journal of Mental Deficiency, 1977, 82, 155-161.

Lonsdale, G. Family life with a handicapped child: the parents speak. Child: care, health and development, 1978, 4, 99-120.

Mitchell, D.R. (ed.). Your Child is Different. Wellington: Continuing Education Unit of Radio New Zealand, 1979 (A revised version is being published by George Allen and Unwin, 1981).

Mitchell, D.R. Special education research by 1990. New Zealand Journal of Educational Studies, 1981(a), 16.

Mitchell, D.R. An evaluation of the integration of moderately intellectually handicapped children into a regular school environment. Occasional Paper in Education. Hamilton: University of Waikato, 1981(b).

Mitchell, D.R. A survey of parents' experiences and views on being told they have a handicapped child. New Zealand Medical Journal, 1981.

Mitchell, D.R., Parker, M. and Ward, R. Beyond Expectations: Early Intervention with Down's Syndrome Infants. Occasional Paper No.3, Project PATH, University of Waikato, 1981.

Mittler, P.J. People Not Patients. London: Methuen, 1979.

Morrison, A.A., Beasley, D.M.G. and Williamson, K.I. The Intellectually Handicapped and Their Families. Wellington: The Research Foundation of the New Zealand Society for the Intellectually Handicapped, 1976.

Mussen, P.H., Conger, J.J. and Kagan, J. Child Development and Personality, Fifth Edition. New York: Harper and Row, 1979.

National Development Group for the Mentally Handicapped. Mentally Handicapped Children: A Plan for Action. Pamphlet Number 2. London: Her Majesty's Stationery Office, 1979.

New Zealand Society for the Intellectually Handicapped. Philosophy and Policy. Wellington: NZSIH, 1979.

Parker, M. and Mitchell, D.R. Parents as Teachers of the Handicapped: A Review. Occasional Paper No. 1, Project PATH, University of Waikato, 1980.

Pueschel, S.M. and Murphy, A. Assessment of counseling practices at the birth of a child with Down's Syndrome. American Journal of Mental Deficiency, 1976, 81, 325-220.

Pulman, R.J. Medical services for parents of the mentally retarded as perceived by New Zealand parents. Mental Handicap in New Zealand, 1979(a), 4, 4-15.

Pulman, R.M. Parents' perceptions of counselling about Down's Syndrome: An interim report. New Zealand Nursing Forum, 1979(b), 7, 7-9.

Reynolds, A.R. Some social effects of the mentally retarded child on the family: a third survey. Australian Journal of Mental Retardation, 1979, 5, 214-218.

Richards, I.D.G. and McIntosh, H.T. Spina bifida survivors and their parents: a study of problems and services. Developmental Medicine and Child Neurology, 1973, 15, 292-304.

Salk, L., Hilgartner, M. and Grunich, B. The psycho-social impact of hemophilia on the patient and his family. Social Science and Medicine, 1972, 6, 491-505.

Sanson-Fisher, R. and Maquire, P. Should skills in communicating with patients be taught in medical schools. The Lancet, September 6, 1980, 523-526.

Sax, P. Counselling parents of handicapped children: the evolution of a broadened perspective. Paper presented to Education Department, Lethbridge University, 1980.

Siegel, S. Nonparametric Statistics for the Behavioural Sciences. New York: McGraw Hill, 1956.

Singer, J.E., Westphal, M. and Niswander, K.R. Sex differences in the incidence of neonatal abnormalities and abnormal performance in early childhood. Child Development, 1968, 39, 101-112.

Smith, M.G. Disabled People : A Select List of Recent Books. Auckland: Auckland Public Library, 1981.

Smith, V.J. The social history of community care of the disabled. In J.S. Dodge and J.M. Dodge (eds.). Community Care of the Disabled. Dunedin: Department of University Extension, University of Otago, 1979.

Somerville, A., Barnett, P. and Malcolm, C. The intellectually handicapped in North Canterbury: A basis for service planning. Planning and Research Series No. 1, Health and Planning Research Unit, North Canterbury Hospital Board, 1976.

Spain, B. and Wigley, G. Right from the Start. London: National Society for Mentally Handicapped Children, 1975.

Svarstad, B.L. and Lipton, H.L. Informing parents about mental retardation: a study of professional communication and parent acceptance. Social Science and Medicine, 1977, 11, 645-651.

Threlfall, S. The counselling of parents. In A.F. Laing (ed.). Young Children with Special Needs. Swansea: Department of Education, University College of Swansea, 1979.

Wahlstrom, V. and Sterner, R. Normalising and integrating the whole family. Swedish National Association for Mentally Retarded Children, Youth and Adults, 1978.

Waikato Branch, New Zealand Federation of University Women. Children with Special Needs: A Handbook for Parents of Handicapped Children. Box 7065, Hamilton, 1979.

Walker, J.H. Thomas, M. and Russell, I.T. Spina bifida - and the parents. Developmental Medicine and Child Neurology, 1971, 13, 462-476.

Warnock, H.M. (Chairman). Special Educational Needs : Report of the Committee of Enquiry into the Education of Handicapped Children and Young People. London: H.M.S.O., 1978.

Webb-Hendy, V.E. and Mitchell, D.R. Professionals' opinions of the needs of parents of handicapped children following diagnosis. Mental Handicap in New Zealand, 1981, 6, 9-19.

Wilkin, D. Caring for the Mentally Handicapped Child. London: Croom Helm, 1979.

Wilson, A.P. A Survey of School-Age Cerebral Palsied Children and Their Mothers. Unpublished M.A. thesis, University of Auckland, 1975.

Wolraich, M.L. and Reiter, S. Training physicians in communication skills. Developmental Medicine and Child Neurology, 1979, 21, 773-778.